DEVELOPMENT OF THE FUNCTIONAL MOBILITY ASSESSMENT - FAMILY CENTERED VERSION

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Pediatric wheeled mobility devices require periodic updating to accommodate children's physical growth, changing needs, and device maintenance requirements. Valid and reliable instruments are needed to facilitate the WMD assessment process and to evaluate the effect of new WMDs on clients' functional status. While the Functional Mobility Assessment (FMA) is currently available for use with adults, no similar instrument has been developed for children. In this dissertation study, the Functional Mobility Assessment-Family Centered Version (FMA-FC) was developed to fill this void in assessment technologies. Content validity of the FMA-FC was established qualitatively using interviews with parents/caregivers and therapists with expertise in WMD assessment. Using the relevance scale, quantitative content validity of the FMA-FC Beta Version 1, as rated by parents/caregivers was 92 percent and as rated by therapists was 99 percent. Parents/caregivers and therapists indicated that the meaning of items was clear and all items were easy to rate. Both test-retest reliability (ICC = .85) and internal consistency (Cronbach's alpha = .87) of FMA-FC Beta-Version 3 were found to be acceptable.

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PREFACE

KEY MAKERS

Some people see a closed door and turn away.
Others see a closed door, try the knob,
if it doesn’t open… they turn away.
Still others see a closed door,
try the knob,
if it doesn’t open,
they find a key,
if it doesn’t fit…
they turn away.
A rare few see
a closed door,
try the knob,
if it doesn’t open,
they find a key,
if it doesn’t fit…
They make one.

1.0 INTRODUCTION

In 2011, the United States Census Bureau estimated that 12.1% of the population was disabled. This estimate was derived from responses to the American Community Survey. The types of disabilities cited by the Bureau were visual, hearing, ambulatory, cognitive, self-care, and independent living (see Figure 1). Respondents of all ages were asked questions about disabilities related to hearing and vision; respondents 15 years and older were asked questions about independent living, and respondents 5 years and older were asked questions about

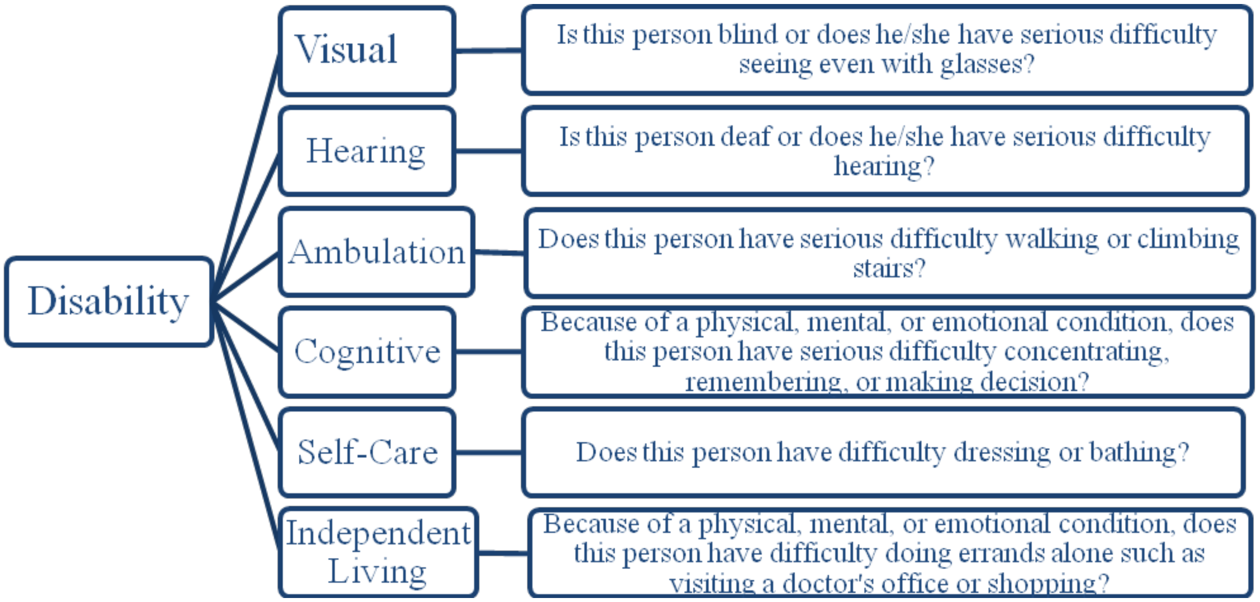


Figure 1. American Community Survey Disability Determinations

(Erickson, Lee & von Schrader, p. 3, 2012).

cognition, ambulation and self-care (Erickson, Lee, & vonSchrader, 2012). Ambulation disability had the highest prevalence at 6.9 percent (see Table 1).

The focus of this study is on pediatric ambulation disabilities of such magnitude that a wheeled mobility device (WMD) has been prescribed. In the October 2010 Fact Sheet on Wheelchairs (World Health Organization, 2010), the World Health Organization (WHO) reported that “the wheelchair is the most commonly used assistive device for enhancing person mobility” (p. 1). The WHO went on to address an individual’s right to have an appropriate wheelchair, and emphasized that the wheelchair provides benefits beyond enhanced mobility. It further outlined the following five criteria necessary for a wheelchair to be considered **appropriate**:

> 1. Meets the user’s needs and environmental conditions
> 2. Provides proper fit and postural support
> 3. Is safe and durable
> 4. Is available in the country; and
> 5. Can be obtained, maintained and services sustained in the country at an affordable cost (p. 2)

Although criteria 2 and 3 can be measured and assessed by the therapist providing the wheelchair; criterion 4 is regulated by the Food and Drug Administration (FDA) in the United States of America; and unless the wheelchair is being paid for by the patient, monies used to satisfy criterion 5 are controlled by funding sources such as insurance companies and the Centers for Medicare and Medicaid Services (CMS). As far as satisfying criterion 1, only the patients using the wheelchairs can truly determine if the wheelchair meets their needs. It is measuring criterion 1 for pediatric patients that continues to elude prescribers, providers, and manufacturers of wheelchairs. Furthermore, in this era of evidence-based practice, with pressure from funding

Table 1. United States Census Bureau 2011 Disability Statistics

Subject	United States									
	Total		With a Disability		%with a Disability		With Ambulatory Disability		% with Ambulatory Disability	
	Base population	Sample size	Estimate	MOE*	Estimate	MOE	Estimate	MOE	Estimate	MOE
Total Civilian non-institutional population	307,593,600	3,028,981	37,326,100	159,490	12.1	0.05	19,937,600	120,200	6.9	0.04
Population under 5 years	20,020,800	172,741	159,000	11,090	0.8	3.29	No data	No data	No data	No data
Population 5 to 15 years	45,269,500	416,302	2,328,700	42,300	5.1	0.09	282,900	14,790	0.6	3.29
Population 16 to 20 years	22,177,100	216,901	1,245,200	30,990	5.6	0.14	184,100	11,940	0.8	3.29
Population 21 to 64 years	180,037,400	1,727,008	18,858,600	117,120	10.6	0.06	9,969,000	86,400	5.5	0.05
Population 65 to 74 years	22,261,200	273,391	5,698,400	65,810	25.6	0.26	3,556,000	52,170	16	0.22

* MOE = Margin of Error; Compiled from 2011 Disability Status Report United States (Erickson, Lee, & vonSchrader, 2012)

sources to prove that the recommended equipment is beneficial to the patient, the importance of being able to measure whether the user’s needs are met has been magnified (Fitzpatrick, Davey, Buxton & Jones, 1998).

To address the measurement of WHO criterion 1 for wheelchairs, Patient-Reported Outcomes (PROs) are being used by health care agencies and researchers. Welding and Smith (2013) reported that a “PRO is directly reported by the patient without interpretation of the patient’s response by a clinician or anyone else and pertains to the patient’s health, quality of life, or functional status associated with health care or treatment” (p. 62). The tools used to measure the patient responses are Patient-Reported Outcome Measures (PROMs). PROMs are especially useful because the patients’ responses to questions and scales yield outcomes that cannot be measured directly, and reflect how the patients feel and perceive their ability to function (Wu, 2008).

Although PROMs such as the Functioning Everyday with a Wheelchair (FEW; Mills et al., 2002), and the Functional Mobility Assessment (FMA; Kumar et al., 2012) exist for assessing adult user satisfaction with their wheelchairs, no PROMs exist for measuring wheelchair satisfaction of pediatric patients and their families. Therefore, the aims of this dissertation study were to: (1) Modify the adult FMA into the FMA-FC (Functional Mobility Assessment – Family-Centered version), (2) Establish the psychometric properties of the FMA-FC (content validity, test-retest reliability and internal consistency).

Chapter 2 defines family-centered care and focuses on adult PROMs that measure satisfaction with wheelchairs, their strengths and their limitations. Chapter 3 discusses the methods used to modify the FMA to yield the FMA-FC, and the methods used to gather input about changes to the FMA-FC versions from parents of children who have received a WMD and the therapists who recommend WMDs (qualitative and quantitative validity). Chapter 3 also includes the methods used to establish the psychometrics of the FMA-FC versions. Chapter 4 reports the results of the iterative modifications to the FMA-FC, the qualitative content validity, the quantitative content validity and the test-retest reliability and internal consistency of the FMA-FC. Chapter 5 summarizes the development, and psychometrics of the FMA-FC versions, the limitations of the studies, and recommendations for future research.

2.0 REVIEW OF THE LITERATURE

2.1 BACKGROUND

2.1.1 Patient-Centered Versus Family-Centered Care

Patient-centered care revolves around the patient (Rickert, 2012), and family-centered care revolves around patients and their families, and both have the ultimate goal of improving the outcomes of medical and therapeutic interventions. When a child is the patient, and families are actively involved in the decision making and goal setting, it creates a win-win situation, where there is greater participation in the interventions and follow through of the plan of care, with the end result being better outcomes (American Hospital Association, 2013). According to Benokraitis (2011), "Family is an intimate group of two or more people who (1) live together in a committed relationship, (2) care for one another and any children, and (3) share activities and close emotional ties" (p. 4). A more complete definition of family adopted by the Human Rights Campaign, and health care organizations nationwide, for purposes of hospital-wide visitation policy is:

> "**Family**" means any person(s) who plays a significant role in an individual's life. This may include a person(s) not legally related to the individual. Members of "**family**" include spouses, domestic partners, and both different-sex and same-sex significant others. "**Family**" includes a minor patient's parents, regardless of the gender of either parent. Solely for purposes of visitation policy, the concept of parenthood is to be liberally construed without limitation as encompassing legal parents, foster parents, same-sex parent, step-

> parents, those serving in loco parentis, and other persons operating in caretaker roles (Human Rights Campaign, 2014).

Thus, when the literature addresses “patient-centered care,” the patient is usually an adult, however, for purposes of this dissertation, “patient-centered care” will also mean “family-centered care.”

2.1.2 Patient-Centered Service Delivery and Outcomes

During the 1980’s and 1990’s a paradigm shift occurred in service delivery for individuals with disabilities, from the expert-centered medical model to the client/family-centered social model. Intervention strategies moved from the approach in which individuals were passive participants in their medical care and impairments needed to be fixed or cured, to one in which individuals were valued members of the team and took a more active role in their care. (Butler, 2010)

With the demand for accountability increasing, therapists needed a way under this new model of service delivery to determine the clinical effectiveness of their interventions. One challenge was that the perception of what was important differed greatly between doctors, therapists and patients. Each had their own “unique perceptions, abilities and resources” (Pfeifle, Gussak, & Keegan, 1999 p. 242). Moreover, the paradigm shift changed from only looking at outcomes associated with biological factors, physical factors and disease symptoms to outcomes associated with the patients’ perspectives --- what they could do following the intervention compared to the level of functioning before the intervention (Pfeifle et al., 1999). Table 2 illustrates outcome differences among professionals, caregivers and patients based on focus, function, and importance of function. Hewlett (2003) reported that therapists failed to understand the importance of function to the patient because therapists were looking to either fix the problem or find ways around it while patients wanted to continue performing that function.

Harris, Pinnington and Ward (2005) reviewed 18 mobility outcome measures but stated that none focused clearly on social participation. Wu (2010) further delineated differences among outcomes reported by therapists, caregivers, and patients (see Table 3). Therapists reported on the results from various tests of function and observations. Physiological outcomes included normal versus abnormal laboratory values, as well as organ abnormalities. Caregivers reported on the patient's functional status and associated burden of care, while patients reported their well-being, satisfaction with functional status, and on the quality of care they received.

Table 2. Differences in Perspectives of Clinical Outcomes

Outcome	Professional's perspective	Caregiver's perspective	Patient's perspective
Focus	Patient's physical health status	Patients' physical health status	Psychological effects
Function	Rate the ability to perform	Dependency	Pain and effort it takes to perform tasks
Importance of function	Fix/ways around problems	Burden of care	Desire to continue performing valued function

(Hewlett, 2003, pp. 877-879)

Table 3. Categories of Patient Outcomes

Categories of patient outcomes	Examples
Therapist-reported	Global impressions, observations and tests of function
Physiological	Laboratory abnormalities, tumor size
Caregiver-reported	Dependency, burden of care, functional status
Patient-reported	Global impressions, functional status, well-being, symptoms, health-related quality of life, satisfaction with treatment, treatment adherence, utility/preference-based measures.

(Wu, 2010)

2.2 CONCEPTS MEASURED WITH PATIENT-REPORTED OUTCOME MEASURES

According to Fitzpatrick et al. (1998), after the paradigm shift and the determination that PROMs would provide the most meaningful outcomes to the patient, the next decision was to determine which would be the most appropriate, reliable, valid, responsive, precise, interpretable, acceptable and feasible instrument to use. Eight major types of PROM tools have been described (Fitzpatrick et al., 1998; Patrick et al., 2007; Patrick & Guyatt, 2013) (see Table 4). Some types of PROM tools have a specific focus or purpose. For example, disease-specific, site of region-specific, and population-specific tools should not be administered to samples that do not have the disease, impairments, or population characteristic. Dimension-specific tools can focus on a specific health issue, such as pain, but miss issues impacting a person's broader health status. With the generic questionnaires comparisons across different groups are possible, but the level of detail, in terms of relevance to any illness may be sacrificed. Summarized items provide indicators of health changes, but the trade off is that details are lost. For individualized tools, the advantage is that the subject matter is relevant to the patient, but with items so individualized it takes more resources to analyze the data. Utility measures focus on a specific health question, asking patients to weigh how much they are willing to risk three outcomes (excellent quality of life, chronic health condition for the rest of life, death) in order to receive a high-risk intervention. However, some patients find it hard to understand how to make such decisions under uncertain conditions (Gafni, 1994).

Table 4. Patient-Reported Outcome Measures (PROMs), by Type

Type of PROMs	Examples	Considerations
Disease-specific	Asthma Quality of Life Questionnaire, Arthritis Impact Measurement Scales	These tools should be responsive to clinically important changes associated with the disease/condition .
Site or region specific	Oxford Hip Score, Shoulder Disability Questionnaire	These tools focus on specific body parts or regions of the body.
Population-specific	Child Health and Illness Profile-Child Edition (CHIP-CE)	These tools target specific populations, such as age groups, gender, etc.
Dimension-specific	Beck Depression Inventory, McGill Pain Questionnaire	These tools focus on one specific dimension of health status, such as pain.
Generic	Short Form (36) Health Survey (SF-36), Functional Limitations Profile	Generic tools focus on broad perceptions of health status and/or health behaviors.
Summary items	Question about limitations from long standing illness in the General Household Survey	Summarized items in a larger tool are quick to administer but lack specificity.

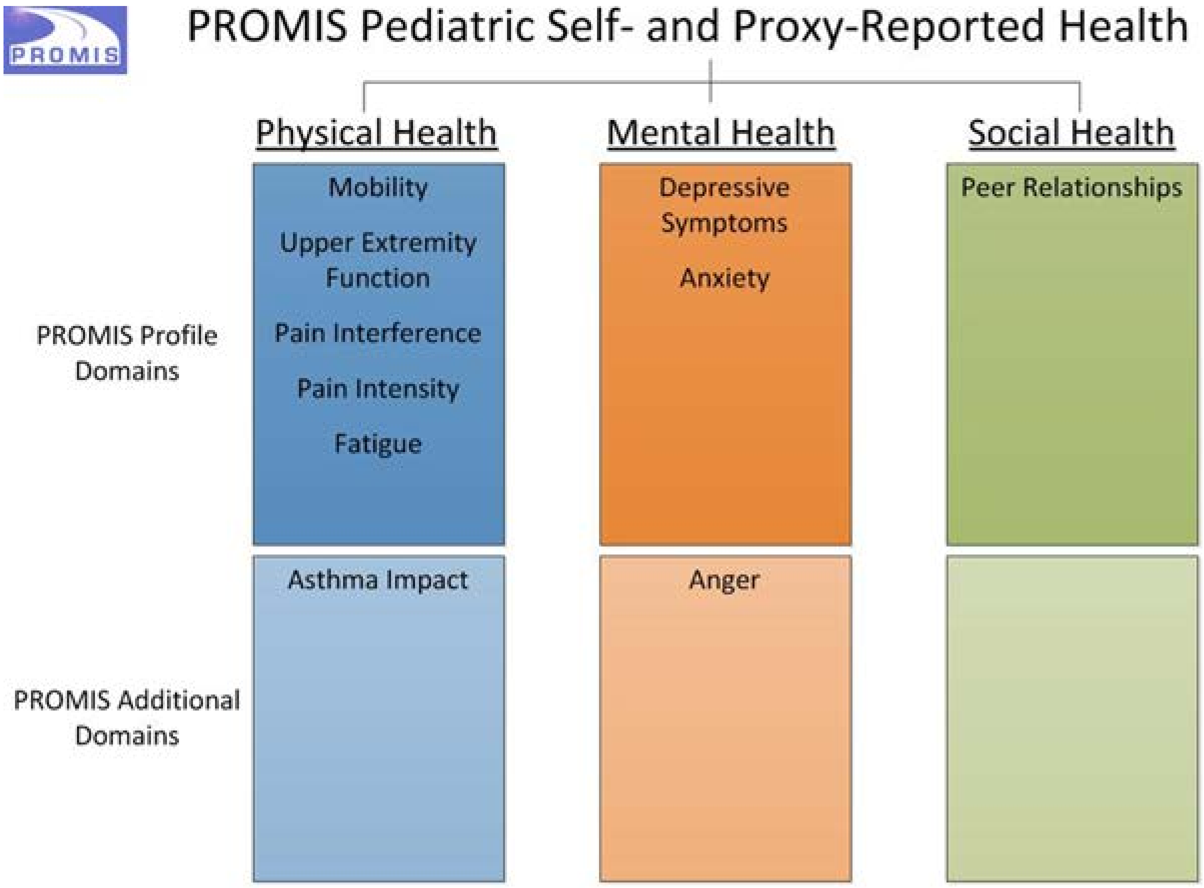
Table 4 (continued)

Individualized	McMaster Toronto Arthritis patient preference questionnaire (MACTAR), Schedule for the Evaluation of Individual Quality of Life (SEIQoL), Canadian Occupational Performance Measure	Individualized tools allow individuals to choose issues to rate that are important to them.
Utility	Standard Gamble Method, Time Trade Off Method	Utility tools focus on patient preferences under uncertain conditions

2.3 PATIENT-REPORTED OUTCOME MEASURES OF MOBILITY

2.3.1 Concepts Measured with the Patient-Reported Outcome Measurement Information System (PROMIS) for Pediatrics

Recently, the National Institutes of Health (NIH) funded project, Patient-Reported Outcome Measurement Information System (PROMIS), developed a bank of patient-reported items for use in instruments for adults and children (PROMIS, 2014a). The goal of the project is to measure what patients are able to do and how they feel by asking questions (PROMIS, 2014b). The instrument formats consist of a short form (4 - 10 items per concept) or a computerized adaptive testing format (4 - 7 items per concept). All PROMIS items have 5 response options (e.g., 1 = Not at all, 2 = A little bit, 3 = Somewhat, 4 = Quite a bit, 5 = Very much), except for the pain item which has 11 response options (0 = No pain and 10 = Worst imaginable pain). Most PROMIS items have a 7 day recall, meaning that the questions begin with…"in the past 7 days…" Currently, 66 instruments are available to measure the following domains: Anxiety, Anger, Depression, Fatigue, Pain Behavior, Pain Interference, Satisfaction with Discretionary Social Activities, Satisfaction with Social Roles, Sexual Function, Global Health, and Physical function. For Physical Function, instruments are available for adults and children, as well as a parent proxy report for pediatric patients. The PROMIS Pediatric Self- and Proxy Profile domains include mental health, social health and physical health. The physical health domain for pediatrics includes instruments to measure mobility (see Figure 2).



12/12/2012

Figure 2. Patient-Reported Outcome Measurement Information Systems for Pediatrics (PROMIS, 2014b)

2.3.1.1 PROMIS Pediatric Bank v1.0 (Mobility)

The PROMIS Pediatric item bank was developed to be used with children between the ages of 8 and 17 years. The Pediatric Mobility bank consists of 23 items that begin with…"in the past 7 days I could…." Most of the items refer to standing, walking, running, and moving around. One item, 2709R1, reads: "In the past 7 days I used a wheelchair to get around" (PROMIS, 2014c).

2.3.1.2 PROMIS Pediatric Short Form v1.0 (Mobility).

The Short Form of the PROMIS Pediatric Mobility instrument consists of 8 items which address getting up and down, standing, playing and doing sports and exercises with other children. Each item offers the following response options: (a) with no trouble, (b) with a little trouble (c) with some trouble (d) with a lot of trouble, and (e) not able to do. No item refers to a wheelchair (PROMIS, 2014d).

2.3.1.3 PROMIS Parent Proxy Bank v1.0 (Mobility)

The 23 item Parent Proxy Bank was developed to parallel the Pediatric Mobility item bank (Varni et al. 2012). The wording was changed from In the past 7 days I… to In the past 7 days my child… Each item offers the following response options: (a) with no trouble, (b) with a little trouble (c) with some trouble (d) with a lot of trouble, and (e) not able to do. As with the Pediatric Bank only one item, Pf4mobil7r, reads: In the past 7 days my child used a wheelchair to get around (PROMIS, 2014e).

2.3.1.4 PROMIS Parent Proxy Short Form v1.0 (Mobility)

The PROMIS Parent Proxy Short form consists of 8 items which also address getting up and down, standing, playing and doing sports and exercises with other children. Each item offers the following response options: (a) with no trouble, (b) with a little trouble (c) with some trouble (d) with a lot of trouble, and (e) not able to do. No item refers to a wheelchair (PROMIS, 2014f).

2.3.2 Mobility Concepts Measured with the National Institutes of Health (NIH) Toolbox

The NIH Toolbox Motor Domain is designed to measure dexterity, grip strength, standing balance, locomotion and endurance of individuals aged 3 – 85 years of age, except for the locomotion item, which has an age range of 7-85. Locomotion consists of a 4 meter walk gait speed test, and endurance consists of a 2 minute walk endurance test. No items address use of a wheelchair (NIH Toolbox, 2014).

2.3.3 Mobility Concepts Measured with the Neuro-QOL Pediatric Scale v1.0 (Lower Extremity Function – Mobility)

The Neuro-QOL Pediatric Scale for mobility consists of 53 items addressing an individual's ability to move, stand, and walk. The tool also includes 21 items on wheelchair mobility and begins by asking the child: Which of the 4 statements best describes you? (a) I use a wheelchair all of the time. I never walk, (b) I use a walking device at least some of the time and a wheelchair at least some of the time, (c) I use a cane, walker or other walking device at least some of the time, but I never use a wheelchair, and I never use a walking device or a wheelchair. Once mobility status is established the child then responds to the 53 items.

For example, one of the statements chosen could be: In the past 7 days I could move up and down curbs using a wheelchair… and a pull down menu provides the following options: (a) with no trouble, (b) with a little trouble (c) with some trouble (d) with a lot of trouble, and (e) not able to do (Neuro-QOL, 2014).

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2.4 WHEELCHAIR OUTCOME MEASURES

Brault (2012) reported that in 2010, 56.7 million individuals in the US had a disability. This represented 18.7% of the civilian, non-institutionalized population. For children under the age of 15 years, 5.2 million or 8.4% presented with a disability. He further reported that 2.6 million of those children had a severe disability. With a severe mobility disability being defined as unable to perform one or more functional activities (walking, using stairs, lifting/carrying, or grasping small objects), for ages 15 years and older, and using a wheelchair, cane, crutches or walker for those children 6 years and older. See Table 5 for the breakdown of disability statistics by age ranges. In particular there were 67,000 children between the ages of 6 and 14 years who were reported to use a wheelchair. The use of a wheelchair has the potential to impact the quality of an individual's life and it has more benefits that just enhancing mobility (WHO Fact sheet, 2010). The impact can be positive or it can be negative if the wheelchair does not provide the appropriate fit and postural support (WHO criterion 2). Even though it can be safe and durable (criterion 3), be available in the country (criterion 4), and can be obtained, maintained and serviced at a reasonable cost to the individual (criterion 5), if it does not meet the needs of the individual (criterion 1), it can be as useful to the individual as a wheelchair with square wheels (see Figure 3).

Table 5. Pediatric Disability Statistics (numbers in thousands)

Category	Number		Percentage	
	Estimate	Margin of Error	Estimate	Margin of Error
Under 15 years	**62,176**	******	**100.0**	**(x)**
With a disability	5,218	271	8.4	0.4
Severe Disability	2,601	172	4.2	0..3
Under 3 years	**12,676**	**118**	**100.0**	**(x)**
With a disability	289	77	2.3	0.6
With a developmental delay	258	64	2.0	0.5
Difficulty moving arms & legs	92	63	0.47	0.5
3 to 5 years	**12,961**	**154**	**100.0**	**(x)**
With a disability	465	76	3.6	0.6
With a developmental delay	398	70	3.1	0.5
Difficulty walking, running, or playing	194	50	1.5	0.4
6 to 14 years	**36,540**	**88**	**100.0**	**(x)**
With a disability	4,646	221	12.2	0.6
Severe disability	1,945	146	5.3	0.4
Not severe disability	2,519	182	6.69	0.5
Difficulty walking or running	580	78	1.6	0.2
Used a wheelchair or similar device	67	241	0.2	0.1
Use a cane, crutches, or walker	47	22	0.1	0.1

Adapted from Brault (2012) (x) = Not Applicable
** = The estimate is controlled. A statistical test for sampling is not appropriate.

Mortenson and Auger (2008) completed a comprehensive literature review of wheelchair assessment tools using the WHO International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) as a framework. They searched peer-reviewed articles using the keywords: *function, activity, assistive technology, wheelchair(s), psychometrics, responsiveness, sensitivity to change, questionnaires, participation, outcome assessment,*

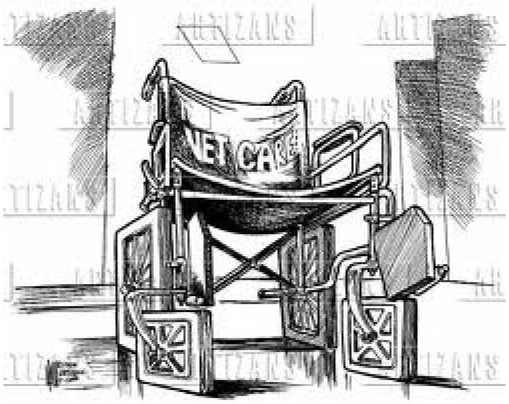


Figure 3. Wheelchair with Square Wheels

(www.artizans.com)

outcomes, treatment outcomes, reproducibility of results, validity and validation studies. They identified 58 wheelchair–specific tools but were able to exclude 47 due to the particular focus of the tool (e.g., physical activity as exercise, metabolic equivalence of physical activity). Grading the remaining 11 tools on conceptual appropriateness, reliability, validity, responsiveness, usefulness, and wheelchair contributions they found most focused on the measurement of wheeled mobility capacity to use a wheelchair in a standardized setting. However, one tool, the Functional Evaluation in a Wheelchair Questionnaire (FEW-Q) examined what meaningful activities the wheelchair allowed users to do rather than what movements users did in the wheelchair. The recommendations from this study were further testing and development of wheelchair-specific outcomes to measure treatment effectiveness and efficacy (how the wheelchair supported meaningful daily activities), because that is what funding sources and healthcare administrators need.

2.4.1 Functioning Everyday with a Wheelchair (FEW) Version 2

The Functioning Everyday with a Wheelchair (FEW) is a self-report tool developed from consumer generated information to measure consumer perceived satisfaction with their wheelchair (Mills et al., 2002; see Appendix A). The study population was manual wheelchair, power wheelchair and scooter users over the age of 18 years. Individuals answer mobility related activities of daily living (MRADL) questions related to (1) stability, durability and dependability, (2) comfort needs, (3) health needs, (4) operate, (5) reach, (6) transfers, (7) personal care, (8) indoor mobility, (9) outdoor mobility and (10) transportation while seated in their wheelchairs. Consumers answered the 10 questions for their current wheeled mobility device (Time 1), and again 7 days later (Time 2) to establish test-retest reliability. Responses were scored using an ordinal scale from 1 (completely disagree) to 6 (completely agree), with an option for does not apply. The intraclass correlation coefficients (ICCs) showed an overall test-retest reliability of 0.86, demonstrating that the FEW was stable over time (Mills, Holm, & Schmeler, 2007).

Schein, Schmeler, Holm, Saptano, and Brienza (2010) used the FEW to establish inter-rater reliability between an expert therapist at a telerehabilitation (TR) remote wheelchair clinic location using videoconferencing and an in-person (IP) therapist. Each therapist assessed the wheeled mobility and seating needs of patients recruited from 5 remote clinics in Western Pennsylvania. The TR was equally as effective as the IP in meeting the needs of the subjects for 9 of the 10 FEW items. Responses from subjects were rated from 1-6 ranging from completely disagree (1) to completely agree (6). The majority of responses were mostly agree (5). Transportation was the only area in which the pretest-posttest agreement was less than 5 but the authors explain that the “transportation” item included both personal and public transportation and public transportation was not available to those living in rural areas.

Schmeler (2005) established the ability of the FEW to measure change following an intervention. The subjects were 25 individuals with progressive and non-progressives disorders who had experienced a change in their functional status and needed a new wheeled mobility device. Subjects were tested twice while in their current wheelchair (Time 1), and in their new wheelchair (Time 2). The tools used to assess change after intervention were the FEW, the Functional Abilities in a Wheelchair (FAW), and the FEW-Capacity (FEW-C). Using Cohen's d to assess the effect size of change in the subject's self-reported functional abilities, the FEW showed the largest total effect for change at 3.18, the FAW at 2.46 and the FEW-C at 2.28 indicating that there is a consistent difference in functional abilities between Time 1 and Time 2.

2.4.2 Functional Mobility Assessment (FMA)

The Functional Mobility Assessment (FMA) was developed from the FEW to include individuals who were non-wheelchair users as well as wheelchair users (see Appendix B). The non-wheelchair users included individuals using canes, walkers and crutches and people who did not yet use a mobility device (Kumar et al., 2012). The FMA follows the same protocol and procedures as the FEW with its 10 question self-report format and the rating scale for the MRADLs performed while using whatever means of mobility they currently use. The wording of the questions was modified to include devices used by non- wheelchair users. Test-retest reliability of the FMA was established with a sample of 41 participants (20 non-wheeled mobility device users and 21 existing wheeled mobility device users). The intraclass correlation coefficient (ICC) showed an overall test-retest reliability of 0.87, demonstrating that the FMA was stable.

2.5 NEED FOR A PEDIATRIC WHEELCHAIR OUTCOME MEASURE

Current PROMs, including the PROMIS and NIH Toolbox do not include adequate outcomes for individuals, especially children, who require the use of a wheelchair as their main means of mobility. Although the Neuro-QOL includes many items that address the use of a wheelchair for mobility, most items focus on movement of the wheelchair, rather than functioning with the wheelchair. Furthermore, proxy-reported outcomes, in which someone who is not the patient responds as if they were the patient, is not an acceptable method of reporting outcomes (U.S. Department of Health and Human Services, 2009). However, measurement of PRO of young children and/or adolescents who have cognitive impairments or are unable to communicate because of serious illness still need to be addressed. Therefore, the aims of this dissertation study were to (a) modify the adult FMA into the FMA-FC (Functional Mobility Assessment – Family-Centered version) outcome measure, and (b) establish its content validity, test-retest reliability, and internal consistency.

3.0 METHODS

This mixed-method study was conducted in three phases (see Figure 4). Phase I of the study involved modifying the items and phrasing of the adult FMA so that items were appropriate for administration to families of pediatric wheelchair users. This phase yielded the FMA-FC Beta-Version 1. Phase II focused on establishing the qualitative content validity of the FMA-FC and collecting data for the quantitative content validity, first with parents/caregivers and then with practicing physical therapists and occupational therapists. Qualitative content validity was established by having parents/caregivers and practicing therapists identify what they believed to be essential FMA-FC concepts and phrasing. The content changes suggested by parents/caregivers yielded the FMA-FC Beta-Version 2, and those suggested by practicing therapists yielded the FMA-FC Beta-Version 3. In Phase III, quantitative content validity was established using data collected in Phase II and analyzed consistent with the principle proposed by Lawshe (1975). Two additional psychometric properties of the FMA-FC Beta-Version 3 were also established, namely test-retest reliability and internal consistency.

Phase I ↓	**Modification of the adult FMA items and phrasing to be consistent with a family-centered approach** *Yield: FMA-FC Beta-Version 1*
Phase II ↓	**Qualitative Content Validity: Parents/caregivers** *Yield: Parent/caregiver qualitative content validity* *FMA-FC Beta-Version 2* **Qualitative Content Validity: Therapists** *Yield: Therapist qualitative content validity* *FMA-FC Beta-Version 3*
Phase III	**Psychometric Properties of the FMA-FC Beta-Versions 1, 2 and 3** *Yield: Parent/Caregiver quantitative content validity of FMA-FC Beta Version 1* *Therapist quantitative content validity of FMA-FC Beta Version 2* *Test-retest reliability of the FMA-FC Beta-Version 3* *Internal consistency of the FMA-FC Beta-Version 3*

Figure 4. Study Design

3.1 HUMAN SUBJECTS APPROVAL

Pending approval from the University of Pittsburgh's Institutional Review Board for Human Subjects Research, support was granted from the Scientific Advisory Committee at Children's Specialized Hospital to recruit parents/caregivers of children who used mobility devices and therapists who recommended mobility devices. Two studies were approved by the University of Pittsburgh Institutional Review Board for Human Subjects Research. The Phase II study (qualitative content validity) was approved for qualitative interviews and participant ratings of

FMA items and a written consent form was waived in lieu of verbal consent. The Phase III study was approved for a parent/caregiver test-retest reliability study and required a consent form (see Appendix C).

3.2 PHASE I: MODIFICATION OF THE FMA TO YIELD THE FMA-FC

The PI, in consultation with the Dissertation Committee, modified items of the adult FMA so that item content and phasing was consistent with a family-centered approach to care (see Appendix D).

3.3 PHASE II: QUALITATIVE CONTENT VALIDITY

3.3.1 Participants

Participants in this study were parents/caregivers of children who utilize a WMD, and physical and occupational therapists who evaluate children and make recommendations for WMDs.

3.3.2 Parent/Caregiver Inclusion/Exclusion Criteria and Recruitment

Inclusion criteria for parent/caregiver participation in the study were: (1) must have a child who uses a manual or power wheelchair as the primary means of mobility; (2) must be the primary caregiver for the child at least 6 months prior to participating in the qualitative interview; (3) the child must be between 3 years and 21 years of age (school age); (4) the child must have used a wheelchair for at least 6 months. Exclusion criteria for parent/caregiver participation in the study were: (1) families requiring interpreter services; (2) families who cannot communicate over the telephone; (3) the caregiver is unable to provide consent and a legal representative is not available to provide consent; (4) the child has a progressive disorder.

Fliers with inclusion/exclusion criteria and the purpose of the study were given to parents/caregivers who attended their child’s outpatient therapy appointments by their treating therapists (see Appendix E). Those who were interested in the study were instructed to contact the principal investigator (PI). The PI explained the purpose of the study and the interview groups, including that the sessions would be recorded so that the PI could review the discussion. If the parents/caregivers were willing to participate, the PI proceeded with scheduling a time for the interview.

For the FMA-FC to be generalizable, attempts were made to balance the genders of the children using the WMD, as well as their ages. Therefore, when the parents/caregivers of 5 children of one gender were recruited, the focus changed to recruit 5 children of the opposite gender. Likewise, for age, when parents/caregivers of 5 children of either gender, ages 3-12 (preschool/grade school) were recruited, the focus switched to recruit parents/caregivers of 5 children of either gender, ages 13-21 (middle/high school).

3.3.3 Therapist Inclusion/Exclusion Criteria and Recruitment

Inclusion criteria for therapist participation in the study were: (1) licensed occupational therapist or physical therapist; (2) job responsibilities must include evaluation and recommendation of WMD for pediatric patients. The exclusion criterion for therapist participation in the study was having less than 1 year of clinical practice in the area of seating and wheeled mobility. Multiple interview group times were offered to meet the scheduling needs of participants. Fliers were sent through the Therapy WMD Consortium of Children's Specialized Hospital, and included the subject criteria and the purpose of the study (see Appendix F). Therapists also told other therapists who met the criteria and gave them fliers if they were interested. Those who were interested were instructed to contact the PI. The PI explained the purpose of the study and the interview group, including that the session would be recorded so that the PI could review the discussion. If the therapists were willing to participate, the PI proceeded with scheduling an interview.

3.3.4 Sample Size

A target of approximately 10 participants was set for parents/caregivers and 10 participants for therapists, or until saturation was reached, meaning that no new changes were suggested by the participants. Although it was the intent to interview parents/caregivers and therapists in small groups, scheduling conflicts prevented this from happening consistently. Instead, for parents/caregivers there were 4 separate interviews (n = 5; n = 3; n = 1; n = 1). Likewise, for therapists, there were 4 separate interviews (n = 2; n = 6; n = 1; n = 1).

3.3.5 Procedures

The parent/caregiver interviews were conducted first. A questionnaire focused on the following demographics was given to the parent/caregiver to complete before the interviews began: (a) child demographics, (b) parent/caregiver demographics, (c) family demographics, (d) what was important to consider when selecting a WMD for their child (see Appendix G). With each interview, the PI used a script (see Appendix H) and began by asking participants if they had reviewed the FMA-FC Beta-Version 1. If participants had not reviewed it, the PI reviewed it with them. Next, the PI asked parents/caregivers: (a) what is most important to you when considering WMD for your child? (b) what is most important to your child? (c) what is most important to your family? Participants were then asked to rate the FMA-Beta-Version 1 items for relevance (5 = completely relevant; 1 = completely irrelevant) (see Phase III, quantitative content validity), clarity (5 = completely clear; 1 = completely unclear), and ease of rating (5 = completely easy; 1 = completely not easy) (see Appendix I). Next, participants were asked if items should be added, and which items should be kept, modified or deleted. Following discussion about each item, recommendations for change were recorded. With each subsequent set of interviews, the PI did not disclose recommendations made during previous interviews until the current participant(s) made any recommendations for change. Then the previous recommendations were revealed and the current participant(s) discussed whether they agreed with them. The final content revisions of the FMA-FC Beta-Version 1 from the parent/caregiver interviews became the FMA-FC Beta-Version-2 (see Appendix J), which is the tool the therapists reviewed, discussed and rated.

For the therapist interviews, the PI first asked participants to complete a questionnaire focused on the following demographics: (a) general clinical experience, (b) experience recommending WMDs, and (c) involvement of parents in selecting a WMD for their child (see Appendix K). Using a script (see Appendix L), the PI then asked the therapists (a) what do you think is most important to a child when considering a WMD? (b) what do you think is most important to families? Therapists then evaluated the relevance (see Phase III, quantitative content validity) of each item of the FMA-FC Beta-Version 2, as well as the clarity, and ease of rating the item using the same scale as the parents/caregivers (see Appendix I). Participants were then asked if items should be added to the FMA-FC Beta-Version 2, and which items should be kept, modified or deleted? Again, at the end of each therapist interview after participants had made any recommendations for change, recommendations made during previous therapist interviews were shared, and the participant(s) stated whether they agreed with the recommendations. Recommendations for change made by the therapist participants yielded FMA-FC Beta-Version 3 (see Appendix M).

3.4 PHASE III: PSYCHOMETRIC PROPERTIES OF FMA-FC VERSIONS

3.4.1 Quantitative Content Validity

3.4.1.1 Participant Recruitment and Criteria

Participants for the quantitative validity study were Phase II parents/caregivers and therapists. Recruitment procedures and inclusion/exclusion criteria are described in the Phase II study.

3.4.1.2 Sample Size

Ten parents/caregivers and 10 therapists participated in the quantitative validity study. Characteristics of each sample were discussed previously under Phase II.

3.4.1.3 Procedures

In Phase II participants rated the relevance of each item. Those data constituted the quantitative content validity data for the FMA-FC Beta-Version 1 (10 parent/caregiver raters), and the FMA-FC Beta-Version 2 (10 therapist raters). Data were analyzed using the principle proposed by Lawshe (1975) regarding item relevance, gathered from FMA-FC Beta-Versions 1 and 2 in Phase II. Additionally, the FMA-FC Beta-Version 3 document was evaluated by 28 parents/caregivers for test-retest reliability and internal consistency.

3.4.2 Test-Retest Reliability and Internal Consistency Analyses

3.4.2.1 Participant Recruitment and Criteria

Parents/caregivers were recruited from the Outpatient Services of Children's Specialized Hospital. Inclusion/exclusion criteria were the same as for the Phase II parent/caregiver qualitative content validity study (see 3.3.2).

3.4.2.2 Sample Size

A target of 30 participants was chosen for test-retest analyses because it was an adequate number for an ICC. Similarly, the sample size was adequate for the internal consistency analysis.

3.4.2.3 Procedures

Fliers with inclusion/exclusion criteria and the purpose of the study (see Appendix N) were given to parents/caregivers who attended any of the mobility device clinics by their treating therapists. Those who were interested were instructed to contact the PI. The PI explained the purpose of the study, and the fact that the parent/caregiver would receive a telephone call in 7-14 days after completing the face-to-face interview. If the parent/caregiver was willing to participate, the PI proceeded with obtaining consent (see Appendix C for the consent form). The PI used a script (see Appendix O), administered the FMA-FC Beta-Version-3, and had the parent/caregiver complete the demographics questionnaire. A copy of the FMA-FC Beta-Version-3 was given to the parent/caregiver to take home, and a telephone interview was scheduled 7-14 days later, thus using the same procedure as Mills et al. (2002) and Kumar et al. (2012).

For the FMA-FC to be generalizable, attempts were made to balance the genders of the children using the WMD, as well as their ages, for a target of 30 subjects. Therefore, when the parents/caregivers of 15 children of one gender had been recruited, the focus would be to recruit 15 children of the opposite gender. Likewise, for age, when parents/caregivers of 15 children of either gender, ages 3-12 (grade school) had been recruited, the focus would be to recruit parents/caregivers of 15 children of either gender, ages 13-21 (middle/high school).

3.4.3 Data analyses

3.4.3.1 Sample Characteristics

Descriptive statistics were used to describe the parents/caregivers who participated in the interviews and the test-retest reliability study as well as their children and family constellations. Tables were created to describe representative responses by parents/caregivers to the following questions: (a) what is important when considering a WMD for your child? (b) what is important to your child? and (c) what is important to your family?

Descriptive statistics were also used to describe the therapists who participated in the interviews, their experience, and their caseloads. Tables were created to describe representative responses by therapists to the following questions: (a) what is important to parents/caregivers when considering a WMD for their child? (b) what is important to families?

3.4.3.2 Rating Successive Versions of the FMA-FC

Likewise, descriptive statistics were used to describe how participants of the parent/caregiver interviews rated each item of the Beta-Version-1 of the FMA-FC for relevance, clarity, and ease of rating. Recommended modifications to the FMA-FC Beta-Version-1 by parents/caregivers yielded Beta-Version-2. The therapists then rated Beta-Version-2 of the FMA-FC, yielding Beta-Version-3, which was used for the test-retest study. Each iteration of the FMA-FC and its modifications were described.

3.4.3.3 Content Validity

Ratings for each respective version of the FMA-FC (version-1, parents/caregivers; version-2, therapists) were then dichotomized (relevant/not relevant) to establish content validity. Completely relevant, mostly relevant and slightly relevant were categorized as relevant. Mostly irrelevant and completely irrelevant were categorized as not relevant. For each version of the FMA-FC the percentage of each of the 10 interview participants rating the item as relevant constituted the item's quantitative content validity, using the principle proposed by Lawshe (1975): “The more panelists (beyond 50%) who perceive the item as “essential,” the greater the extent or degree of its content validity” (p. 567).

3.4.3.4 Item Clarity, Ease of Rating, Keeping an Item, and Item Priority

For clarity of the item, completely clear, mostly clear and slightly clear were categorized as clear, and mostly unclear and completely unclear were categorized as not clear. For ease of rating the item, completely easy, mostly easy and slightly easy were categorized as easy, and mostly not easy and completely not easy were categorized as not easy.

For each item, participants recommended to keep, delete, or modify it. The percentage recommending keeping an item was reported, as well as any recommended modifications. Parents were also asked to rate the priority of each item for their children, with 10 being the most important and 1 being the least important. However, parents found it difficult to rank the 10 items, so instead they were asked to rank their top 3 items for their child, with 1 being most important and 3 being least important.

3.4.3.5 Test-retest Reliability and Internal Consistency

Intraclass correlation coefficients (ICC, 3*k*) were used to calculate the test-retest reliability for each item and the total score of the Beta-Version-3 FMA-FC, with a target of $\geq$ 0.75 (Portney & Watkins, 2009). According to Portney and Watkins (2009) test-retest reliability values closer to 1.00 represent the strongest reliability, and values $\geq$ 0.75 indicate good reliability. Those below 0.75 range from moderate to poor reliability. Cronbach's alpha was used to assess the internal consistency of the Beta-Version-3 FMA-FC, with a target of 0.70 – 0.90 for acceptable internal consistency without redundancy (Briggs & Cheek, 1986).

4.0 RESULTS

The results are presented sequentially by study phase. However, data for the qualitative and quantitative aspects of content validity were collected in an integrated manner and are presented together for each item. Quantitative content validity is discussed as a unit in section 4.3.1. To facilitate locating specific data, the organization of the chapter is presented in Figure 5.

Phase I	**Modification of the adult FMA items and phrasing to be consistent with a family-centered approach** *Yield: FMA-FC Beta-Version 1*
Phase II	**Sample characteristics and perceptions about important WMD factors** *Yield: Parent characteristics* *Child characteristics* *Parent/caregiver perceptions of the FMA-FC Beta-Version* *WMD factors important to parents/caregivers, their children and families* *Therapist characteristics* *WMD factors important to therapists* **Qualitative content validity** *Yield: Successive content iterations of FMA-FC Beta Versions 2 and FMA-FC Beta-Version 3*
Phase III	**Psychometric Properties of the FMA-FC Beta-Version 3** *Yield: Test-retest sample characteristics* *Quantitative content validity of FMA-FC Beta-Versions 1 & 2* *Test-retest reliability of the FMA-FC Beta-Version 3* *Internal consistency of the FMA-FC Beta-Version 3*

WMD = wheeled mobility device

Figure 5. Organization of Results

4.1 PHASE I: MODIFICATION OF THE ADULT FMA

As shown in Appendix C, the adult FMA items and phrasing were modified by the PI, in consultation with the Dissertation Committee, to be consistent with a family-centered approach. Most of the modifications involved making the child the subject of the item as opposed to an adult respondent. For example, the FMA item “My current means of mobility…” was changed to “My child’s current means of mobility…” followed by the content of the item. The response scale (completely agree, 100%; mostly agree, 80%; slightly agree, 60%; slightly disagree, 40%; mostly disagree, 20%; completely disagree, 0%, and does not apply) remained as it is in the adult version of the FMA (see Appendix D).

4.2 PHASE II: SAMPLE CHARACTERISTICS AND PERCEPTIONS

4.2.1 Parent/Caregiver Characteristics

As seen in Table 6, the greatest number of parents/caregivers interviewed were in the 41-50-year age range. Only three parents/caregivers identified respiratory or physical impairments. Parents/caregivers were primarily concerned with postural support and independence when seeking a WMD for their child.

Table 6. Demographic/Health/Family-Parent/Caregiver Data

Demographic/Health/Family Data	**Interview Participants (N = 10)**
Age of parent/caregiver (n)	
19 or younger	1
20 – 30 years	0
31 – 40 years	3
41 – 50 years	4
51 – 60 years	1
61+ years	1
Parent/caregiver impairments (n)	
Respiratory impairment	1
Musculoskeletal impairment	1
Neuromuscular impairment	1
Important factors for my child's mobility device (n)*	
Postural support	9
Mobility of the device in the environment	6
Transportability of the device	6
Independence of my child using the device	7

*More than one factor could be identified

4.2.2 Child Characteristics of Parent/Caregiver Interview Participants

The demographics for the children of the parents/caregivers can be found in Table 7. The children of the 10 parent/caregiver participants ranged in age from 9 to 18. Gender and age distributions were equivalent. On average, the children had their current WMD for nearly 4 years and spent an average of 8 hours a day in their WMDs. Equal numbers of their children used manual and power WMDs. All but one child had a diagnosis of cerebral palsy. Parents/caregivers identified that their children's primary impairments were musculoskeletal and neuromuscular. Parent/caregiver family size ranged from three to nine, with their child with a disability most often being the first born.

Table 7. Demographic/Health/Family – Child Data

Demographic/Health/Family Data	**Interview Participants (N = 10)**
Demographics/Health - Child	
Age of child using WMD (Mean Years) (Range in years)	13.50 (9 – 18)
Gender and ages (n)	
Males < 13 years	2
Males ≥ 13 years and < 22 years	3
Females < 13 years	2
Females ≥ 13years and < 22 years	3
Age of child's WMD (Mean Years) (Range in years)	3.75 (1 – 12)
Hours child spends in WMD per day (Mean Hours) (Range in hours)	8.71 (4 – 14)
My child's current WMD (n)	
Manual	4
Power	4
Unknown	2
My child's diagnostic condition (n)	
Cerebral palsy	9
Traumatic brain injury	1
My child's impairments (n)	
Child has musculoskeletal impairment*	6
Child has neuromuscular impairment*	6

N.B. WMD = wheeled mobility device; *children can have more than one impairment

Table 7 (Continued)

Demographic/Health/Family Data	**Interview Participants (N = 10)**
Number in the family (n)	
3	2
4	4
5	3
9	1
Birth order of the child in the family (n)	
First	5
Second	3
Third	2

4.2.3 Parent/Caregiver Perceptions About Their Child's WMD

Responses to open-ended questions asked of parents/caregivers on the demographic form are reported in Table 8. During discussions about the WMDs used by their children, the majority of the parents/caregivers reported that their children required considerable assistance to transfer across surfaces. They also discussed what they liked and did not like about their child's system. For likes, they reported independence for their child and device characteristics, such as light weight and tilt. For dislikes, they reported device characteristics related to bulk or being too heavy, poor postural support, lack of durability of parts and difficulty maneuvering. Most of the families transported their child in modified vans with occupant restraints, which allowed the children to remain seated in the WMD during transport. To sum up their experience with their child's WMD, the majority of the parents/caregivers felt that the WMD used by their child allowed them to do what they wanted to do together as a family unit.

Table 8. Representative Responses to Demographic Form Open-Ended Questions

Representative responses to open-ended question: How much assistance does your child need for transfers
• 100% • 70% • Can do but very slow • Minimal • Minor
Representative responses to open-ended question: What do you like about your child's WMD?
• Allows independence/freedom for my child • Light and easy to maneuver/roll • Chair tilts and reclines • Fitted for posture/comfort • Nothing
Representative responses to open-ended question: What don't you like about your child's WMD?
• Too heavy/bulky • Difficult to transport • Doesn't support posture • Can't/difficult fold • Parts/repair
Representative responses to open-ended question: What type of vehicle do you use to transport your child?
• Wheelchair accessible Van • Rear entry Van • Van • Modified Van • Conversion Van
Representative responses to open-ended question: Is your vehicle equipped with WMD tie downs and occupant restraint systems?
• No • Yes • Has E-Z Lock system • Has Bruno Lift • Has wheelchair tiedown and occupant restraint system
Representative responses to open-ended question: Does the WMD allow your family to do what you want to do as a family unit?
• Yes • Definitely • Mostly • Sometimes • Not really

WMD = wheeled mobility device

When parents/caregivers discussed what was important to them when considering a WMD for their child, their responses fell into four categories: (1) impact on the child (e.g., optimal positioning, comfort and safety, (2) impact on the parents/caregivers (e.g., independence for caregivers, ability to do things as a family, safety), (3) characteristics of the WMD (e.g., transportability, maneuverability, weight, durability), (4) responsiveness of the DME supplier (e.g., timely service and repairs, knowledge and experience of the DME supplier) (see Table 9).

When parents/caregivers discussed what WMD factors would be important to their child, many of the responses were similar to those features they thought important when considering a WMD for their child (e.g., maneuverability, safety, durability, independence). However, some parents/caregivers also spoke of the need for easy access to a variety of environments and surfaces, reliability, and compatibility with the child's electronics. Ability to participate in activities with family and friends was also deemed to be important to their child (see Table 10).

Parents/caregivers, when asked what WMD factors would be important to families, spoke mostly of WMD equipment characteristics and activities that they could do as a family. Similar to previous responses, safety, durability and reliability of the WMD and its equipment were mentioned. However, having a place for a sibling to ride on the WMD and having different chairs or equipment for different activities were new issues. Also for families, the ability to travel together and a WMD that allowed their child to participate in all family activities was deemed desirable (see Table 11).

Table 9. WMD factors important to parents/caregivers (not prioritized)

Impact on Child	**Impact on Parents/caregivers**	**Characteristics of WMD**	**Responsiveness of DME Supplier**
Optimal positioning to help preserve neck, back, hips and spine alignment	Independence for parent/caregiver	Transportability	Ability to service/repair WMD in a timely manner
Comfortable	Aesthetics (not too bulky looking)	Size	Knowledge and experience of representative to <u>assist</u> in decision making
Safety (arms extending when passing through doorways)	We can do things together as a family	Indoor and outdoor maneuverability	
Independence for child	Safety (hands/fingers getting caught in spokes of drive wheels)	Safety (WMD not tippy)	
Freedom to go places	Transition outdoors to indoors	Quality of product	
		Durability for active user	
		Weight	
		Ease of adjustability of parts	
		Ease of parts springing back	

WMD = wheeled mobility device

Table 10. Parent/Caregiver Perceptions of What About a WMD is Important to Their Child

Impact on Child	Characteristics of WMD
Independence	Height adjustable equipment
Ability to participate in activities with family and friends	Waterproof/water-resistant
Comfort	Maneuverability
Safety	Perks (e.g., name on back of cushion)
Not be limited by the size and weight of the WMD	Durable equipment
Compatible electronics – computer, environmental controls	Compatible electronics – computer, environmental controls
Easy access to variety of environments & surfaces	Reliability so they know they will no get stuck if something breaks
Not limited by inability of WMD to adapt to different terrains	Speed
	Looking Cool

WMD = wheeled mobility device

Table 11. Parent/Caregiver Perceptions of What About WMD is Important to Families

Characteristics of WMD	**Activity**
Accessibility	Family activities TOGETHER
Ease of getting WMD into car/van	Travel in one vehicle together
Safety	Travel on an airplane
Different chairs/parts for different activities	Ease of getting in/out of car
Spring-loaded tippers that move out of the way up/down curb and spring back	Not to be limited to where we could take our child due to the fact that he is in a wheelchair
Bearings in wheels	
Space on wheelchair for siblings/friends	
Reliable wheelchair and parts	
Size of device	
Durability of parts	
Stability of WMD	
Service availability	
Storage for personal equipment	

WMD = wheeled mobility device

4.2.4 Therapist Characteristics

The therapist participants (as seen in Table 12) consisted of 9 physical therapists and 1 occupational therapist. Their clinic experience ranged from 16 to 36 years; 3 to 36 years of recommending WMD. Participating therapists were employed at a Children's Specialized

Hospital facility, LADACIN Network, Lakeview School, and 1st Cerebral Palsy of NJ. The primary age ranges for the therapist caseloads was 3-6 years and 13-18 years with the majority of their families being very involved in the evaluation and selection of the WMD for their child.

Table 12. Therapist data

Therapist characteristics	
Discipline (n)	
Physical therapy	9
Occupational therapy	1
Years of practice, mean (range)	27.1 (16 – 36)
How many years have you recommended wheeled mobility devices, mean (range)	19.8 (4 – 36)
Caseload number of patients per month, mean (range)	32.3 (2 – 100)
Age ranges of patients on your caseload (n)*	
< 3 years	4
3 – 6 years	8
7 – 12 years	2
13 – 18 years	8
Level of family involvement in WMD selection (n)	
Not at all involved	0
Somewhat involved	1
Very involved	8

*Therapists may have patients in more than one age category

When therapists discussed what the WMD factors they perceived as important to the children, their responses were similar to those of the parents/caregivers (e.g., electronics compatibility, access, reliability, independence). Therapists also mentioned accessibility to backpack items, having lots of flashy functions, looking “cool,” and ability to transfer with ease (see Table 13).

When therapists discussed the WMD factors they perceived as important to families, their responses fell into three categories: (1) impact on the child, (2) impact on the parent, (3) characteristics of the WMD. Responses categorized under impact on the child included issues such as support of medical/health challenges, comfort, and looking “normal.” Responses categorized under impact on parent included issues such as wanting someone else to pay for the WMD, supporting proper alignment of their child, and ease of use for the caregiver. Responses categorized under characteristics of the WMD included items such as service and repair access, transportability, weight, and adjustability of the WMD (see Table 14).

Table 13. Therapist Perceptions of WMD Factors Important to the Child

Important to the Child	WMD Factors
Independent mobility	Looks cool
Access to playground	Compatibility of electronics – Bluetooth, iPhone
Independent as possible with all functions	Lots of functions--- bells and whistles; up/down, back/forth
Able to play with friends	Horn; flashing lights
Go where friends and family go	Placement and accessibility of backpack (easy access to phone, supplies, etc.)
Have people notice them--NOT their WMD	Fast
Look good in whatever WMD they are in	Ease of use
Transport of sibling	Reliability so they know they won't get stuck if something breaks
Ease of transfer in/out	
Comfortable	

WMD = wheeled mobility device

Table 14. Therapist Perceptions of WMD Factors Important to Families

Impact on Child	Impact on Parent	Characteristic of WMD
Support medical/health challenges	Ease of use for caregiver	Service, maintenance and repair readily available
Comfort	Cost; want someone else to pay	Adjustability
Independence	Aesthetics	Light weight – portable/foldable
Easy to use for child	Convenient for caregiver	Durable
Looks nice	Low profile	Compact as possible
Low profile	Normal (non-medical) looking	Allows for change of position
Normal looking	Want their child to like it	Transportable
	Support proper alignment	Can use it in home and out in community
	Manageable for parent	Use on all terrains

WMD = wheeled mobility device

4.3 PHASE II: QUALITATIVE CONTENT VALIDITY: FMA-FC SUCCESSIVE ITERATIONS

In the following pages, the qualitative content validity discussions from the parent/caregiver interviews and the therapist interviews are described along with ratings of items relevance (quantitative content validity) and other aspects of instrument utility. The parents/caregivers first reviewed the FMA-FC Beta-Version 1, and each participant rated each item for relevance, clarity, and ease of rating. They then discussed whether the item should be retained as is, modified, or deleted. On average, parents/caregivers recommended keeping the FMA-FC Beta-Version 1 items and phrasing as they were 90 percent of the time. Recommended changes they wanted to see in each item or phrasing were made, and that tool became FMA-FC Beta-Version 2. The same procedure was followed with the practicing therapists. In contrast to parents/caregivers, on average, therapists recommended keeping the FMA-FC Beta-Version 2 items and phrasing as they were only 53 percent of the time. Their recommended changes became FMA-FC Beta-Version 3.

As shown in Table 15, parent/caregiver participants rated the relevance, clarity and ease of rating Beta-Version-1 Item 1 (see Appendix C) at 100%, but after the group discussion, only 8/10 participants recommended keeping the item as it was. However, no specific recommendations for change were made for Beta-Version-2 (see Appendix D). Likewise, the therapist participants rated relevance, clarity, and ease of rating at 100%, with 8/10 recommending keeping the item as it was. Their recommendation was to change the wording “carry out” to “participate in,” which is reflected in Beta-Version-3 (see Appendix E). One other concern voiced by therapists was that parents/caregivers sometimes choose the WMD that is most convenient for them (e.g., to carry up stairs, to stow in the trunk), rather than the needs of their child. However, they could not think of a way to reflect this concern in the FMA-FC .

Table 15. Ratings and Modifications to Beta Versions of the FMA-FC Item 1 (Daily Routines)

<table>
<tr><td colspan="4">**FMA-FC Beta-Version-1**
1. My child’s current means of mobility allows our family to carry out our daily routines as independently, safely and efficiently as possible: *(e.g., tasks we want to do, need to do, are required to do- when and where needed)*</td></tr>
<tr><td>Parent/Caregiver Relevance Rating</td><td>Parent/Caregiver Clarity Rating</td><td>Parent/Caregiver Ease of Rating</td><td>Parent/Caregiver Keep As Is Rating</td></tr>
<tr><td>100%</td><td>100%</td><td>100%</td><td>80%</td></tr>
<tr><td colspan="4">• Parents complained about WMD companies and vendors not standing behind their products and not understanding the impact of the WMD on the whole family…..did not comment on the form
• Parent was unsure of correct wording on the form
• Parent/caregiver discussion also focused on accessibility issues in the environment with a WMD…but did not recommend changes.</td></tr>
<tr><td colspan="4">**FMA-FC Beta-Version-2 (no changes)**
1. My child’s current means of mobility allows our family to carry out our daily routines as independently, safely and efficiently as possible: *(e.g., tasks we want to do, need to do, are required to do- when and where needed)*</td></tr>
<tr><td>Therapist Relevance Rating</td><td>Therapist Clarity Rating</td><td>Therapist Ease of Rating</td><td>Therapist Keep As Is Rating</td></tr>
<tr><td>100%</td><td>100%</td><td>100%</td><td>80%</td></tr>
<tr><td colspan="4">• Prefers “participate with” versus “to carry out”
• Change “independently” to “inclusively”
• Therapists discussed that parents sometimes make decisions about their child’s WMD based on their own convenience (carrying it up stairs/ fitting it into the trunk), rather than their child’s needs---but were unsure how to make any changes to address this</td></tr>
<tr><td colspan="4">**FMA-FC Beta-Version-3 (change)**
1. My child’s current means of mobility allows our family to participate in our daily routines as independently, safely and as easily as possible: *(e.g., tasks we want to do, need to do, are required to do- when and where needed)*</td></tr>
</table>

As shown in Table 16, parent/caregiver participants rated the relevance, clarity and ease of rating Item 2 at 100%, but after the group discussion, only 9/10 participants recommended keeping the item as it was. However, no specific recommendations for change were made for Beta-Version-2. Likewise, the therapist participants rated relevance, clarity, and ease of rating at 100%. However, only 5/10 recommended keeping the item as it was. Their final recommendations were to change the wording “sitting tolerance” to “ability to sit for a long time,” “pain” to “pain free,” and delete the term “stability.” All recommendations are reflected in Beta-Version-3.

Table 16. Ratings and Modifications to Beta Versions of the FMA-FC Item 2 (Comfort)

FMA-FC Beta-Version-1

2. My child's current means of mobility meets his/her comfort needs: *(e.g., heat/moisture, sitting tolerance, pain, stability)*

Parent/Caregiver Relevance Rating	Parent/Caregiver Clarity Rating	Parent/Caregiver Ease of Rating	Parent/Caregiver Keep As Is Rating
100%	100%	100%	90%

- One parent recommended deleting the item because it may not apply to all children

FMA-FC Beta-Version-2 (no changes)

2. My child's current means of mobility meets his/her comfort needs*:* *(e.g., heat/moisture, sitting tolerance, pain, stability)*

Therapist Relevance Rating	Therapist Clarity Rating	Therapist Ease of Rating	Therapist Keep As Is Rating
100%	100%	100%	50%

- Change "tolerance" and "stability"
- Change "tolerance" to "ability to sit for a long time"
- Stability doesn't fit – maybe "maintain balance while completing activities"

FMA-FC Beta-Version-3 (change)

2. My child's current means of mobility meets his/her comfort needs: *(e.g., heat/moisture, ability to sit for a long time, pain free)* [deleted stability]

As shown in Table 17, parent/caregiver participants rated the relevance, clarity and ease of rating Item 3 at 100%, but after the group discussion, only 9/10 participants recommended keeping the item as it was. The recommendation was to put page numbers on the forms. Likewise, the therapist participants rated relevance, clarity, and ease of rating at 100%. However, only 4/10 recommended keeping the item as it was. Their final recommendations were to change item from “health needs” to “postural support needs” which was deemed more relevant to WMD evaluations. With the change of the item, the associated wording to reflect “postural support needs” was changed to (e.g., no redness or sores on the skin, good support for breathing, decreased or no swelling, maintains sitting balance while completing activities). All recommendations are reflected in Beta-Version-3.

Table 17. Ratings and Modifications to Beta Versions of the FMA-FC Item 3 (Health/Posture)

<table>
<tr><td colspan="4">FMA-FC Beta-Version-1

3. My child's current means of mobility meets his/her health needs: <i>(e.g., pressure sores, breathing, edema control, medical equipment)</i></td></tr>
<tr><td>Parent/Caregiver Relevance Rating</td><td>Parent/Caregiver Clarity Rating</td><td>Parent/Caregiver Ease of Rating</td><td>Parent/Caregiver Keep As Is Rating</td></tr>
<tr><td>100%</td><td>100%</td><td>100%</td><td>90%</td></tr>
<tr><td colspan="4">• Parent commented on where to put page numbers on the forms – not on the content of the form</td></tr>
<tr><td colspan="4">FMA-FC Beta-Version-2 (no changes)

3. My child's current means of mobility meets his/her health needs: <i>(e.g., pressure sores, breathing, edema control, medical equipment)</i></td></tr>
<tr><td>Therapist Relevance Rating</td><td>Therapist Clarity Rating</td><td>Therapist Ease of Rating</td><td>Therapist Keep As Is Rating</td></tr>
<tr><td>100%</td><td>100%</td><td>100%</td><td>40%</td></tr>
<tr><td colspan="4">• Change "health" to something more family focused
• Change to 2 questions: one posture questions and one to durable medical equipment
• Change "edema" to "swelling"
• Change pressure sores to "open wounds, redness or soreness"
• List medical equipment—maybe a new item
• List medical needs such as ventilators, sitting/walking/standing/hip orthosis (SWASH), etc.(new Item??)</td></tr>
<tr><td colspan="4">FMA-FC Beta-Version-3 (change)

3. My child's current means of mobility meets his/her postural support needs: <i>(e.g., no redness or sores on skin, good support for breathing, decreased or no swelling, maintains sitting balance while completing activities)</i></td></tr>
</table>

As shown in Table 18, parent/caregiver participants rated the relevance of item 4 at 90%. Both clarity and ease of rating Item 4 were rated at 100%, but after the group discussion, only 9/10 participants recommended keeping the item as it was. The families preferred the word ”function” rather than “operate.” The therapist participants rated relevance, clarity, and ease of rating at 100%. However, only 5/10 recommended keeping the item as it was. Their discussion was that “function” was actually covered in items 5-10 and as such was redundant here. Since the storage of items was always a concern they wanted to address this. With the change of the item, the associated wording to reflect “managing his/her daily supplies” was changed to (e.g., Medical-ventilator, oxygen, suction, catheter tubing) (Personal- computer, braces, phone, lunch etc.) All recommendations are reflected in Beta-Version-3.

Table 18. Ratings and Modifications to Beta Versions of the FMA-FC Item 4 (Operate/Function)

FMA-FC Beta-Version-1

4. My child's current means of mobility allows him/her to operate as independently, safely and efficiently as possible: *(e.g., do what (s)he wants it to do when and where (s)he wants to do it)*

Parent/Caregiver Relevance Rating	Parent/Caregiver Clarity Rating	Parent/Caregiver Ease of Rating	Parent/Caregiver Keep As Is Rating
90%	100%	100%	90%

- Parent did not answer the Keep As Is item.
- Discussion among families thought "operate" was too narrow, as well as issues with accessibility impacting "operate"
- Operate was too narrow….group preferred "function"

FMA-FC Beta-Version-2 (change)

4. My child's current means of mobility allows him/her to function as independently, safely and efficiently as possible: *(e.g., do what he/she want it to do when and where he/she wants to do it)*

Therapist Relevance Rating	Therapist Clarity Rating	Therapist Ease of Rating	Therapist Keep As Is Rating
100%	100%	100%	50%

- Function covers Items 5-10….maybe change this item to something else.
- Change modifiers (efficient, safe)
- Combine Item 4 with Item 9
- Perform activities with whom they choose?

FMA-FC Beta-Version-3 (change)

4. My child's current means of mobility allows for managing his/her daily supplies*:* *(e.g., Medical – ventilator, oxygen, suction, catheter tubing) (Personal – computer, braces, phone, lunch etc.)*

As shown in Table 19, parent/caregiver participants rated the relevance of item 5 at 90%, clarity 100% and ease of rating 90%, but after the group discussion, only 9/10 participants recommended keeping the item as it was. However, no specific recommendations for change were made for Beta-Version-2. The therapist participants rated relevance and clarity and 90%, and ease of rating at 100%. However, only 2/10 recommended keeping the item as it was. Their discussion was that "carry out" sounded too clinical and should be replaced with "complete," "efficiently" should be replaced with "easily," and "get under desks" should be added. All recommendations are reflected in Beta-Version-3.

Table 19. Ratings and Modifications to Beta Versions of the FMA-FC Item 5 (Reach)

FMA-FC Beta-Version-1

5. My child’s current means of mobility allows him/her to reach and carry out tasks at different surface heights as independently, safely and efficiently as possible: *(e.g., tables, desks, counters, floors, shelves)*

Parent/Caregiver Relevance Rating	Parent/Caregiver Clarity Rating	Parent/Caregiver Ease of Rating	Parent/Caregiver Keep As Is Rating
90%	100%	90%	90%

- Parent did not answer the Keep As Is item

FMA-FC Beta-Version-2 (no changes)

5. My child’s current means of mobility allows him/her to reach and carry out tasks at different surface heights as independently, safely and efficiently as possible*:* *(e.g., tables, desks, counters, floors, shelves)*

Therapist Relevance Rating	Therapist Clarity Rating	Therapist Ease of Rating	Therapist Keep As Is Rating
90%	90%	100%	20%

- Delete item
- Delete because therapists can provide adaptations for different heights
- Change efficiently to easily (X2)
- Modify wording to access surfaces rather than reach
- Add “classroom” desks
- Add “complete tasks”

FMA-FC Beta-Version-3 (change)

5. My child’s current means of mobility allows him/her to access and complete tasks at different surface heights as independently, safely and easily as possible: *(e.g., get under desks, tables, counters, floors, shelves)*

As shown in Table 20, parent/caregiver participants rated the relevance of item 6 at 90%, clarity 100% and ease of rating 90%, but after the group discussion, only 8/10 participants recommended keeping the item as it was. During parent/caregiver group discussion removal of the word “floor” was brought up, and this was reflected in Beta-Version-2. The therapist participants rated relevance, clarity, and ease of rating at 100%. However, only 6/10 recommended keeping the item as it was. Their recommendation was to add “with or without help” as well as “participate” to include individuals that need assistance in completing this task. All recommendations are reflected in Beta-Version-3.

Table 20. Ratings and Modifications to Beta Versions of the FMA-FC Item 6 (Transfer)

FMA-FC Beta-Version-1

6. My child’s current means of mobility allows him/her to transfer from one surface to another: *(e.g., bed, toilet, chair, floor)*

Parent/Caregiver Relevance Rating	Parent/Caregiver Clarity Rating	Parent/Caregiver Ease of Rating	Parent/Caregiver Keep As Is Rating
90%	100%	90%	80%

- Add independently or dependently
- Delete because my child can transfer by herself (did not address the form)
- Remove floor

FMA-FC Beta-Version-2 (change)

6. My child’s current means of mobility allows him/her to transfer from one surface to another: *(e.g., bed, toilet, chair) [floor deleted]*

Therapist Relevance Rating	Therapist Clarity Rating	Therapist Ease of Rating	Therapist Keep As Is Rating
100%	100%	100%	60%

- Add “actively or passively or by themselves with help”
- Add “with or without help”
- Add “ease of transfers”
- Change “to transfer” to “participate” in transfers

FMA-FC Beta-Version-3 (change)

6. My child’s current means of mobility allows him/her to participate (with or without help) in transfers from one surface to another: *(e.g., bed, toilet, chair)*

As shown in Table 21, parent/caregiver participants rated the relevance of item 7 at 60%, and clarity and ease of rating 90%, but after the group discussion, only 8/10 participants recommended keeping the item as it was. Those participants deemed this item was not applicable because the parents not the children completed personal care tasks. However, there were no change to Beta-Version-2. The therapist participants rated relevance, clarity, and ease of rating at 100%. However, only 3/10 recommended keeping the item as it was. Their recommendation was to change “carry out” to “complete,” to add “easily,” “toileting care,” “washing” and “brushing teeth.” All recommendations are reflected in Beta-Version-3.

Table 21. Ratings and Modifications to Beta Versions of the FMA-FC Item 7 (Personal Care)

FMA-FC Beta-Version-1

7. My child's current means of mobility allows him/her to carry out personal care tasks: *(e.g., dressing, bowel/bladder care, eating, hygiene)*

Parent/Caregiver Relevance Rating	Parent/Caregiver Clarity Rating	Parent/Caregiver Ease of Rating	Parent/Caregiver Keep As Is Rating
60%	90%	90%	80%

- Because several parents do the tasks for their children they thought the item irrelevant
- Do not delete because the item may apply to some
- Accessibility to the bathroom was deemed critical--some discussed having to widen doors, while others discussed having to park the WMD outside the bathroom and carry the child into the bathroom

FMA-FC Beta-Version-2 (no changes)

7. My child's current means of mobility allows him/her to carry out personal care tasks: *(e.g., dressing, bowel/bladder care, eating, hygiene)*

Therapist Relevance Rating	Therapist Clarity Rating	Therapist Ease of Rating	Therapist Keep As Is Rating
100%	100%	100%	30%

- Change from "carry out" to "participate in"
- Add "easily"
- Include "toileting"
- Add "bathroom care"
- Change "bowel/bladder" to "toileting care"
- Change to "toileting, dressing, etc."
- Add a space for parents to clarify
- Add "washing" and "brushing teeth"

FMA-FC Beta-Version-3 (change)

7. My child's current means of mobility allows him/her to complete personal care tasks easily: *(e.g., dressing, toileting care, eating, washing, brushing teeth)*

As shown in Table 22, parent/caregiver participants rated the relevance, clarity and ease of rating of item 8 at 100% and after the group discussion, all 10 participants recommended keeping the item as it was. During the discussion families wanted an item added that would include independence from parents/caregivers in social settings. It was decided to combine indoors and outdoors into item and "socialize independently" into item 9. Furthermore, recommendations for item 8 were to separate examples for "indoors" and "outdoors" with additional wording for "outdoors," namely "= uneven surfaces, grass, gravel." These changes were reflected in Beta-Version-2. The therapist participants rated relevance, clarity, and ease of rating at 100%. However, only 7/10 recommended keeping the item as it was. Their recommendation was to add "playgrounds" to the examples. All recommendations are reflected in Beta-Version-3.

Table 22. Ratings and Modifications to Beta Versions of the FMA-FC Item 8 (Indoor/Indoor & Outdoor)

FMA-FC Beta-Version-1

8. My child's current means of mobility allows him/her to get around indoors: *(e.g., home, school, church, mall, restaurants, ramps, obstacles)*

Parent/Caregiver Relevance Rating	Parent/Caregiver Clarity Rating	Parent/Caregiver Ease of Rating	Parent/Caregiver Keep As Is Rating
100%	100%	100%	100%

- Families wanted a "social" item and suggested combining indoors and outdoors
- Add uneven surfaces, grass, gravel

FMA-FC Beta-Version-2 (change)

8. My child's current means of mobility allows him/her to get around indoors AND outdoors: *(e.g., indoors = home, school, mall, restaurants – outdoors = uneven surfaces, grass, gravel, ramps, obstacles)*

Therapist Relevance Rating	Therapist Clarity Rating	Therapist Ease of Rating	Therapist Keep As Is Rating
100%	100%	100%	70%

- Add "playgrounds" (X3)

FMA-FC Beta-Version-3 (change)

8. My child's current means of mobility allows him/her to get around indoors AND outdoors: *(e.g., indoors = home, school, mall, restaurants – outdoors = playgrounds, uneven surfaces, grass, gravel, ramps, obstacles)*

As shown in Table 23, parent/caregiver participants rated the relevance of item 9 at 90% and clarity and ease of rating at 100%, and after the group discussion 9/10 participants recommended the new item 9 discussed with item 8 be “My child’s current means of mobility allows him/her to socialize with other children independent of family caregiver,” which it did for Beta-Version-2. Additionally, the examples for item 9 also changed to “(e.g., mobility device accepted by other children; raises eye level to that of other children for easier socialization).” The therapist participants rated relevance, clarity, and ease of rating at 100%. However, only 5/10 recommended keeping the item as it was. Their recommendation was to reword the item as “to do what he/she wants to do independent of family/caregiver: (e.g. socialize, provide Bluetooth accessibility, accessible to peers).” All recommendations are reflected in Beta-Version-3.

Table 23. Ratings and Modifications to Beta Versions of the FMA-FC Item 9 (Outdoor/ Social Independence)

<table>
<tr><td colspan="4">**FMA-FC Beta-Version-1**
9. My child’s current means of mobility allows him/her to get around outdoors: *(e.g., uneven surfaces, dirt, grass, gravel, ramps, obstacles)*</td></tr>
<tr><td>Parent/Caregiver Relevance Rating</td><td>Parent/Caregiver Clarity Rating</td><td>Parent/Caregiver Ease of Rating</td><td>Parent/Caregiver Keep As Is Rating</td></tr>
<tr><td>90%</td><td>100%</td><td>100%</td><td>100%</td></tr>
<tr><td colspan="4">• Discussion for item 8 included combining items 8 and 9 (indoors & outdoors) and adding a new “socialize” item as item 9
• Wording suggested to be “participate in social activities with peers”
• Parents felt “socialize” was important because as their children grew older they didn’t want to have the parent hanging around, even though they were dependent on the parent</td></tr>
<tr><td colspan="4">**FMA-FC Beta-Version-2 (change)**
9. My child’s current means of mobility allows him/her to socialize with other children independent of family caregiver: *(e.g., mobility device accepted by other children; raises eye level to that of other children for easier socialization)*</td></tr>
<tr><td>Therapist Relevance Rating</td><td>Therapist Clarity Rating</td><td>Therapist Ease of Rating</td><td>Therapist Keep As Is Rating</td></tr>
<tr><td>100%</td><td>100%</td><td>100%</td><td>50%</td></tr>
<tr><td colspan="4">• Take out “children”
• “Socialize with friends, family, peers – independent of family and caregiver
• Include wording from previous #4 (do what he/she wants to do)
• Provide Bluetooth access for socializing with peers</td></tr>
<tr><td colspan="4">**FMA-FC Beta-Version-3 (change)**
9. My child’s current means of mobility allows him/her to do what he/she wants to do independent of family/caregiver: *(e.g., socialize, provide Bluetooth accessibility, accessible to peers)*</td></tr>
</table>

As shown in Table 24, parent/caregiver participants rated the relevance, clarity and ease of rating of item 10 at 100%. Even though all 10 participants recommended keeping the item as it was, during the group discussion it was suggested to add “school” to the transportation list. This change was reflected in Beta-Version-2. The therapist participants rated relevance, clarity, and ease of rating at 100%. However, only 8/10 recommended keeping the item as it was. Their recommendation was to change stow to “fold and store.” This recommendation was reflected in Beta-Version-3.

Table 24. Ratings and Modifications to Beta Versions of the FMA-FC Item 10 (Transportation)

<table>
<tr><td colspan="4">FMA-FC Beta-Version-1
10. My child’s current means of mobility allows him/her to use personal (family car/van) or public transportation as independently, safely and efficiently as possible: <i>(e.g., secure, stow, ride)</i></td></tr>
<tr><td>Parent/Caregiver Relevance Rating</td><td>Parent/Caregiver Clarity Rating</td><td>Parent/Caregiver Ease of Rating</td><td>Parent/Caregiver Keep As Is Rating</td></tr>
<tr><td>100%</td><td>100%</td><td>100%</td><td>100%</td></tr>
<tr><td colspan="4">• Parents discussed adding “school transportation” to transportation</td></tr>
<tr><td colspan="4">FMA-FC Beta-Version-2 (changes)
10. My child’s current means of mobility allows him/her to use school, personal or public transportation as independently, safely and efficiently as possible: <i>(e.g., secure, stow, ride)</i></td></tr>
<tr><td>Therapist Relevance Rating</td><td>Therapist Clarity Rating</td><td>Therapist Ease of Rating</td><td>Therapist Keep As Is Rating</td></tr>
<tr><td>100%</td><td>100%</td><td>100%</td><td>80%</td></tr>
<tr><td colspan="4">• Modify “stow.” Should be “fold and put in trunk”
• Modify “stow.” Should be “fold and store”</td></tr>
<tr><td colspan="4">FMA-FC Beta-Version-3 (changes)
10. My child’s current means of mobility allows him/her to use school, personal or public transportation as independently, safely and easily as possible: <i>(e.g., secure, fold and store, ride)</i></td></tr>
</table>

4.4 PSYCHOMETRIC PROPERTIES

4.3.1 Quantitative Content Validity of the FMA-FC, Clarity and Ease of Rating

Parent/caregiver and therapist ratings of the relevance (content validity), clarity and ease of rating the FMA-FC are summarized in Table 25. Using the principle proposed by Lawshe (1975), "The more panelists (beyond 50%) who perceive the item as "essential," the greater the extent or degree of its content validity" (p. 567). Both parents/caregivers and therapists rated the content validity of the FMA-FC as excellent ($\geq$ 90%), except for the personal care item which parents/caregivers rated as 60%. Likewise, they also rated the clarity of the wording, and the ease of rating the tool as excellent ($\geq$ 90%).

Table 25. Relevance (Content Validity), Clarity and Ease of Rating FMA-FC Items

Items	**Relevance** of the item for supporting child's use of WMD		**Clarity** of the item		**Ease** of rating the item	
	Parents/ Caregivers (N=10) (%)	Therapists (N=10) (%)	Parents/ Caregivers (N=10) (%)	Therapists (N=10) (%)	Parents/ Caregivers (N=10) (%)	Therapists (N=10) (%)
1 Daily Routines	100	100	100	100	100	100
2 Comfort	100	100	100	100	100	100
3 Health/*Posture*	100	100	100	100	100	100
4 Operate/*Function*	90	*100*	100	*100*	100	*100*
5 Reach	90	90	100	90	90	100
6 Transfer	90	100	100	100	90	100
7 Personal Care	60	100	90	100	90	100
8 Indoor/*Indoor & Outdoor*	100	*100*	100	*100*	100	*100*
9 Outdoor/*Social Independence*	90	*100*	100	*100*	100	*100*
10 Transportation	100	100	100	100	100	100
Averages	92	99	99	99	97	100

N.B. Items in *italics* represent changes to FMA-FC Beta-Version 2 based on parent/caregiver feedback

4.3.2 Test-Retest Reliability of the FMA-FC Beta-Version 3

4.3.2.1 Parent/Caregiver Characteristics

As seen in Table 26, the greatest number of parents/caregivers in the test-retest group were in the 41-50-year age range. Only 5 parents/caregivers in the test-retest group reported respiratory or physical impairments. Parents/caregivers were primarily concerned with postural support and transportability when seeking a WMD for the child.

Table 26. Demographic/Health/Family-Parent/Caregiver Data

Demographic/Health/Family Data	**Test-Retest Participants (N = 28)**
Age of parent/caregiver (n)	
19 or younger 20 – 30 years 31 – 40 years 41 – 50 years 51 – 60 years 61+ years	0 1 6 13 4 3
Parent/caregiver impairments (n)	
Respiratory impairment	2
Musculoskeletal impairment	2
Neuromuscular impairment	1
Important factors for my child’s mobility device (n)*	
Postural support	22
Mobility of the device in the environment	16
Transportability of the device	17
Independence of my child using the device	14

*More than one factor could be identified

4.3.2.2 Child Characteristics of Parent/Caregiver Participants

The demographics for the children of the parents/caregivers in the test-retest group can be found in Table 27. The children ranged in age from 7 to 20 years. Gender and age distributions were equivalent. On average, the test-retest children had their current WMD for nearly 3 years, and spent about 8 hours a day in their WMDs. Sixty-six percent of test-retest children used manual WMDs, with fewer using power WMDs and strollers; more than half were diagnosed with cerebral palsy. Parents/caregivers identified that their children’s primary impairments were musculoskeletal and neuromuscular. Test-retest family group size ranged from three to nine, with their child with a disability most often being the first born.

Table 27. Demographic/Health/Family –Child Data

Demographic/Health/Family Data	**Test-Retest Participants (N = 28)**
Demographics/Health - Child	
Age of child using WMD (Mean Years) (Range in years)	12.78 (7 – 20)
Gender and ages	
Males < 13 years	8
Males ≥ 13 years and < 22 years	6
Females < 13 years	7
Females ≥ 13years and < 22 years	7
Age of child's WMD (Mean Years) (Range in years)	2.67 (1 – 6)
Hours child spends in WMD per day (Mean Hours) (Range in hours)	8.54 (1 – 16)
My child's current WMD	[n, %]
Manual	20, 66.6
Power	5, 16.6
Stroller	3, 10.0
Unknown	0, 0.0
My child's diagnostic condition	[n, %]
Cerebral palsy	20, 66.6
Traumatic brain injury	2, 6.7
Genetic disorder	2, 6.7
Seizure disorder	2, 6.7
Diagnosis unknown	2, 6.7
My child's impairments	[n, %]
Child has respiratory impairment*	1, 3.3
Child has musculoskeletal impairment*	13, 43.3
Child has neuromuscular impairment*	9, 30.0
Child has cardiac impairment*	0, 0.0

Table 27 (Continued)

Demographic/Health/Family Data	**Test-Retest Participants (N = 28)**
Number in the family	[n, %]
3	8, 26.7
4	10, 33.3
5	4, 13.3
6	2, 6.7
8	2, 6.7
9	1, 3.3
Birth order of the child in the family	[n, %]
First	15, 50.0
Second	6, 20.0
Third	5, 16.7
Fourth	0, 0.0
Fifth	1, 3.3

N.B. WMD = wheeled mobility device; for impairments, *children can have more than one impairment

4.3.2.3 Test-retest Reliability of the FMA-FC Beta-Version 3

The average time between test and retest was 8.41 days, with 63% of the parent/caregiver interviews completed at day 7, 7.4% completed at days 8, 10, 11 and 14 and 3.7% completed at days 9 and 13. The FMA-FC Beta-Version-3 demonstrated an overall $ICC_{3,k}$ of 0.85 [CI = 0.81-0.89], p. < 0.001, interpreted as good reliability. This exceeded our target of 0.75 for degree of agreement between test and retest (see Table 28). Item ICCs ranged from 0.62 (posture) to 0.92 (daily routines). Individually, daily routines and transportation were above 0.90 and as such exceeded our target, as did comfort, daily supplies, reach, transfer, indoor & outdoor and social independence, which were between 0.80 and 0.90. Posture had a less than ideal test-retest reliability at 0.62.

Table 28. Test-Retest Reliability of the FMA-FC Beta-Version-3 (n=28)

FMA-FC Items	$ICC_{3,k}$ [CI]
1 Daily Routines	0.92 [0.83-0.96]
2 Comfort	0.83 [0.64-0.92]
3 Posture	0.62 [0.17-0.83]
4 Daily Supplies	0.86 [0.66-0.94]
5 Reach	0.80 [0.55-0.91]
6 Transfer	0.89 [0.75-0.95]
7 Personal Care	0.78 [0.42-0.92]
8 Indoor & Outdoor	0.88 [0.74-0.95]
9 Social Independence	0.89 [0.71-0.96]
10 Transportation	0.91 [0.79-0.96]
Total	0.85 [0.81-0.89]

4.3.2.4 Internal Consistency of the FMA-FC Beta-Version 3

Internal consistency of the FMA-FC Beta-Version-3 achieved a standardized alpha of 0.87 (see Table 29). Inter-items correlations were mostly within the range (0.20 to 0.50) that indicates internal consistency of FMA-FC items without redundancy (Briggs & Cheek, 1986). Low correlations were associated with items that were not logically related (e.g., daily routines and posture, $r = 0.18$; comfort and personal care, $r = -0.12$).

Table 29. Cronbach's Alphas of the FMA-FC Beta-Version-3 (n=28)

FMA-FC Items	DR	COM	POS	DS	RCH	TRN	PC	I&O	SOC	TRP
1 Daily Routines (DR)	1.00	0.14	0.18	0.23	0.05	0.50	0.68	0.39	0.43	0.33
2 Comfort (COM)		1.00	0.88	0.55	0.45	0.12	-0.12	0.24	0.27	0.57
3 Posture (POS)			1.00	0.50	0.54	0.18	0.04	0.26	0.32	0.60
4 Daily supplies (DS)				1.00	0.39	0.24	0.22	0.57	0.30	0.65
5 Reach (RCH)					1.00	0.61	0.45	0.62	0.57	0.40
6 Transfer (TRN)						1.00	0.82	0.52	0.38	0.24
7 Personal Care (PC)							1.00	0.46	0.43	0.21
8 Indoor & Outdoor (I&O)								1.00	0.63	0.56
9 Social Independence (SOC)									1.00	0.54
10 Transportation (TRP)										1.00
Overall internal consistency										0.87

4.4 PROPOSED FMA-FC BETA-VERSION-4

Although not a goal of the study, when the test-retest participants completed their ratings, the PI asked the participants if they had any suggestions for wording that would improve their ability to rate the FMA-FC. Most of the recommendations focused on deleting “his/her” from the items and making them more generic. However, one substantive change was recommended for item 10 – Transportation. Parents/caregivers recommended removing the word “independently” from “My child’s current means of mobility allows him/her to use school, personal or public transportation as independently, safely and easily as possible.” Their rationale was that their children could not independently secure their WMDs, nor could they fold and store them independently. Thus the term “independently” in item 10 was removed in FMA-FC Beta-Version-4 (see Appendix P for highlighted changes).

5.0 DISCUSSION

Pediatric wheeled mobility devices require periodic updating to accommodate children's physical growth, their changing device needs, and device maintenance (wear and tear) requirements. Valid and reliable instruments are needed to facilitate the WMD assessment process and to evaluate the effect of new WMDs on clients' functional status. While the Functional Mobility Assessment (FMA) is currently available for use with adult users, no instrument has been developed for use with children. In this dissertation study, the Functional Mobility Assessment-Family Centered Version (FMA-FC) was developed to fill this void in assessment technologies. Content validity of the FMA-FC was established qualitatively using interviews with parents/caregivers and therapists with expertise in WMD assessment. Using the relevance scale, quantitative content validity of the FMA-FC Beta Version 1, as rated by parents/caregivers was 92 percent and as rated by therapists was 99 percent. Parents/caregivers and therapists indicated that the meaning of items was clear and all items were easy to rate. Both test-retest reliability (ICC = .85) and internal consistency (Cronbach's alpha = .87) of FMA-FC Beta-Version 3 were found to be acceptable.

Using the FMA as the starting point for the development of the FMA-FC allowed us to take advantage of the conceptual work previously done on assessment of wheeled mobility. We reasoned that the basic concepts to be measured would be similar for children and adults, although the items would need to be directed for response by children's families rather than adult respondents. Thus, initially, item phrasing was changed from a first person ("My current means…") to a third person ("My child's…) orientation and presented as Beta-Version-1. Review of item concepts by two stakeholder groups – parents/caregivers of child WMD users and expert practitioners in WMD assessment – resulted in the addition of only one new concept, social independence (Item 9). Parents strongly advocated for the addition of this item. In their words, "My child is 100% dependent for physical manipulation and needs and will always need to have someone with him. He just wants to have some time without me hanging around. Last week he went into his therapy session, turned to me and said 'you can leave now'." Another parent shared, "My child wants to play with the other kids but they won't come to him as readily if I am sitting there." The meaning of two other FMA concepts was also altered. The label for Health Needs was changed to Daily Supplies to account for personal (e.g. telephone) as well as medical equipment (e.g., catheter). In addition, Indoor and Outdoor Mobility were combined into one item (Item 8), allowing the FMA-FC to remain a 10 item instrument. Thus, the final version of the FMA-FC measures 10 concepts, each in a separate item: Daily Routines, Comfort, Posture, Daily Supplies, Reach, Transfer, Personal Care, Indoor and Outdoor Mobility, Social Independence and Transportation and retained the six-point rating scale of the adult version.

On the FMA instruments, each concept is rendered concrete through examples that illustrate the intent of the item. These examples were included in the qualitative interview and generated numerous changes. Changes were recommended to accomplish three objectives. The first objective was to use examples that were more inclusive and reduced the emphasis on motor actions. Hence, "to carry out my daily routine" became "to participate in our daily routines," (Item 1); "to transfer from one surface to another" was rephrased "to participate in transfers from one surface to another;" (Item 6) and "to reach and carry out tasks at different surface heights" was revised “to access and complete tasks at different surface heights” (Item 5). Participation could be accomplished with or without assistance. The second objective was to use examples that were more family-friendly and involved less medical jargon. Thus, “sitting tolerance” in Item 2 was rephrased as “maintain sitting balance while completing activities” and “bowel/bladder care” in Item 7 became “toileting care.” Lastly, some examples were seen as more appropriate or of interest to children than to adults. Examples under this objective involve playgrounds (Item 8) and Bluetooth accessibility (Item 9).

In general, the parents/caregivers focused their attention on the FMA-FC concepts, that is, on what the FMA-FC items asked about, or should ask about, functional mobility. Their input was based on their 24-hours-a-day-7-days-a-week care of their child and the issues concerning their child’s WMD. With the addition of social independence, the 10 items were seen as adequate for assessing a family’s objectives for a WMD. However, when parents/caregivers were queried more broadly about what was important to them when seeking a WMD for their child, their responses were more varied and fell into four broad areas: WMD characteristics, the influence of WMD on their child, the influence of the WMD on the parent, and their interactions with the WMD supplier. Of these areas of concern, the FMA-FC targets the influence of the WMD on the child. The characteristics of the WMD that were particularly problematic were the durability of parts (especially footrests and casters) and interference between parts (especially footrests and anti-tip parts with wheelchair tie-downs). Size and maneuverability, in relation to indoor and outdoor use and transitions from one to the other, were common concerns. Heading the list of concerns about the influence of the WMD on the parent was not being limited in participating in multiple activities because of the WMD. In regard to vendors, parents/caregivers were adamant about the critical role that they played in obtaining a WMD. Because families are unfamiliar with this equipment, they are dependent on the knowledge and experience of the supplier.

When appraising the FMA-FC, therapists focused their attention on the examples provided to illustrate the mobility concepts, rather than on the concepts themselves as did the parents/caregivers. In responding, they drew on their years of clinical experience and the vast number of families they have interacted with over the years. Their comments frequently dealt with issues related to health literacy, especially deleting medical jargon (e.g., sitting tolerance) and simplifying phrasing and led to two significant changes to the FMA-FC. First, parents/caregivers were asked to prioritize only three versus ten FMA-FC items for their children. It was noted that some parents/caregivers continued to have difficulty even with the revised instructions. Second, the phrasing of item examples was re-written to reflect more closely an elementary reading level. When the therapists were queried about what was important to families when seeking a WMD for their child, they stressed truly listening to the families concerns what worked and did not work for them. Frustration (tempered by understanding) was expressed about several concerns. One concern was therapist-family interactions about WMD decisions based on convenience rather than what is most functional for the child. For example, choosing a WMD that families can get up the stairs or in/out of the house easier. Another concern was children being left in strollers all the time at home because their power wheelchairs were left at school. The time families spent dismantling and re-assembling WMD to transport them was also voiced.

5.1 PSYCHOMETRICS

The psychometric properties of the iterative versions of the FMA-FC address content validity, test-retest reliability, ad internal consistency. Stakeholder's ratings of the relevance of the 10 concepts to wheeled mobility may be viewed as quantifying their qualitative descriptions. Using the relevance scale, quantitative content validity of the FMA-FC Beta Version 1, as rated by parents/caregivers was 92 percent. Quantitative content validity of the FMA-FC Beta Version 2 as rated by therapists was 99 percent. Both ratings imply excellent content validity. A plausible reason for the somewhat lower rating by the parents/caregivers than the therapists is that the FMA-FC Beta Version 1 did not include the concept of social independence whereas it was included on FMA-FC Beta Version 2. The lower parents/caregivers rating may reflect this absence.

Overall test-retest reliability of the FMA-FC Beta-Version 3, as rated by parents/caregivers yielded an ICC of 0.85, categorized as good reliability, and comparable to the FMA-Adult version (ICC = 0.87). The Posture item had the lowest test-retest reliability (0.62, moderate reliability). Parents reported confusion between the Posture item and the Comfort item leading to inconsistent responses from test to retest. Also affecting test-retest changes was the possibility of an unintended intervention occurring between those 7-14 days that affected the inconsistent responses of parents/caregivers. For example, one parent/caregiver did report that a trip to the local amusement park resulted in a change in her response. Where she originally reported that her son was 100% able to transfer across surfaces and 100% mobile in his indoor and outdoor mobility at the test rating, after their trip in which they encountered new environments, she rated him at 80% for the retest. One parent/caregiver put it simply "it could be what happened the day before that causes a change…people's lives change from minute to minute."

The overall internal consistency of the FMA-FC Beta-Version 3 was calculated at 0.87. Individual Cronbach's Alpha correlations ranged from -0.12 for the inter-relatedness of comfort and personal care to 0.88 for the inter-relatedness of comfort and posture. Items with negative alpha values have no inter-item relatedness and as such are apparently measuring different constructs. For example, with comfort and personal care, comfort is an item that is associated with heat/moisture and the ability <u>of the child</u> to sit for a long time. In contrast, the personal care tasks were associated with dressing, and toileting care were <u>completed by many of the parents/caregivers</u>, and thus the relationship is negligible. Similarly, daily routines, a broad item addressing participation in the overall daily routines of a family did not correlate well with items that were child-specific, such as reach, comfort, and posture.

5.2 SUMMARY

The modification of the FMA-Adult version into the FMA-FC yielded a comparable tool, with two exceptions: the FMA-FC added a social independence item and combined indoor and outdoor mobility. While the concepts being measured remained essentially the same between the two versions, the response format changed from first person to third person, and the examples changed --- making them more relevant to children. The content validity of the first two iterative versions of the FMA-FC remained stable at 92% and 99%, and the test-retest validity of the third version of the FMA-FC was good and comparable to the FMA-Adult version (ICC = 0.85 and 0.87, respectively). Internal consistency of the FMA-FC was also good (0.87).

5.3 STUDY LIMITATIONS.

Our study, like all studies has strengths as well as limitations. One limitation is the sequential manner in which content validity of the FMA-FC was ascertained with input first from parents/caregivers and then therapists. This concern is mitigated by the fact that the functional mobility concepts were identified by the parents/caregivers and were not changed by the therapists. Nonetheless, the manner in which these concepts are illustrated substantively influences user ratings and may require additional clarification or development.

A second limitation is the small sample size (10 parents/caregivers; 10 therapists) in conjunction with the application of two data gathering methods – individual and group interviewing. Although the parents/caregivers of children with WMD were willing to participate in the study, finding a common time and convenient place for them to gather proved exceptionally challenging. Because our assessment development was piggybacked on the FMA-Adult version, a draft instrument (FMA-FC Beta-Version I), devised by the PI, was available to spur discussion. By including individual interviews, we were able to obtain data from parents/caregivers who were interested in the aims of the project, but who otherwise could not have provided their input.

5.4 FUTURE RESEARCH.

The FMA-FC is designed to be used by physical and occupational therapists when they meet with parents/caregivers to assess the WMD needs of their children. Importantly, it is intended to be used as an outcome measure to evaluate changes in function between use of an old and new

WMD. While preliminary psychometric work has been done on the FMA-FC, its responsiveness (ability to detect change) needs to be evaluated. Before wide distribution, additional work may be needed on the functional examples used to illustrate each functional mobility item. This need stems from the ambiguity expressed about the distinction between posture and comfort and the additional suggestions made by parents/caregivers in the test-retest sample. Further, it may be useful to consider an FMA-FC version for adolescents. Additionally, this study focused on one WMD, wheelchairs. Before the FMA-FC can be considered valid and reliable for other WMD, further research needs to be done which focuses on each specific WMD.

Of the four areas of concern expressed by parents/caregivers, only one (how the WMD influences the child) is captured by the FMA-FC. Evaluation tools directed at their other three concerns – characteristics of the WMD, influence of the WMD on the family, and the process of purchasing a WMD – would provide a useful addition to the assessment technology of WMD.

APPENDIX A

FUNCTIONING EVERYDAY WITH A WHEELCHAIR (FEW

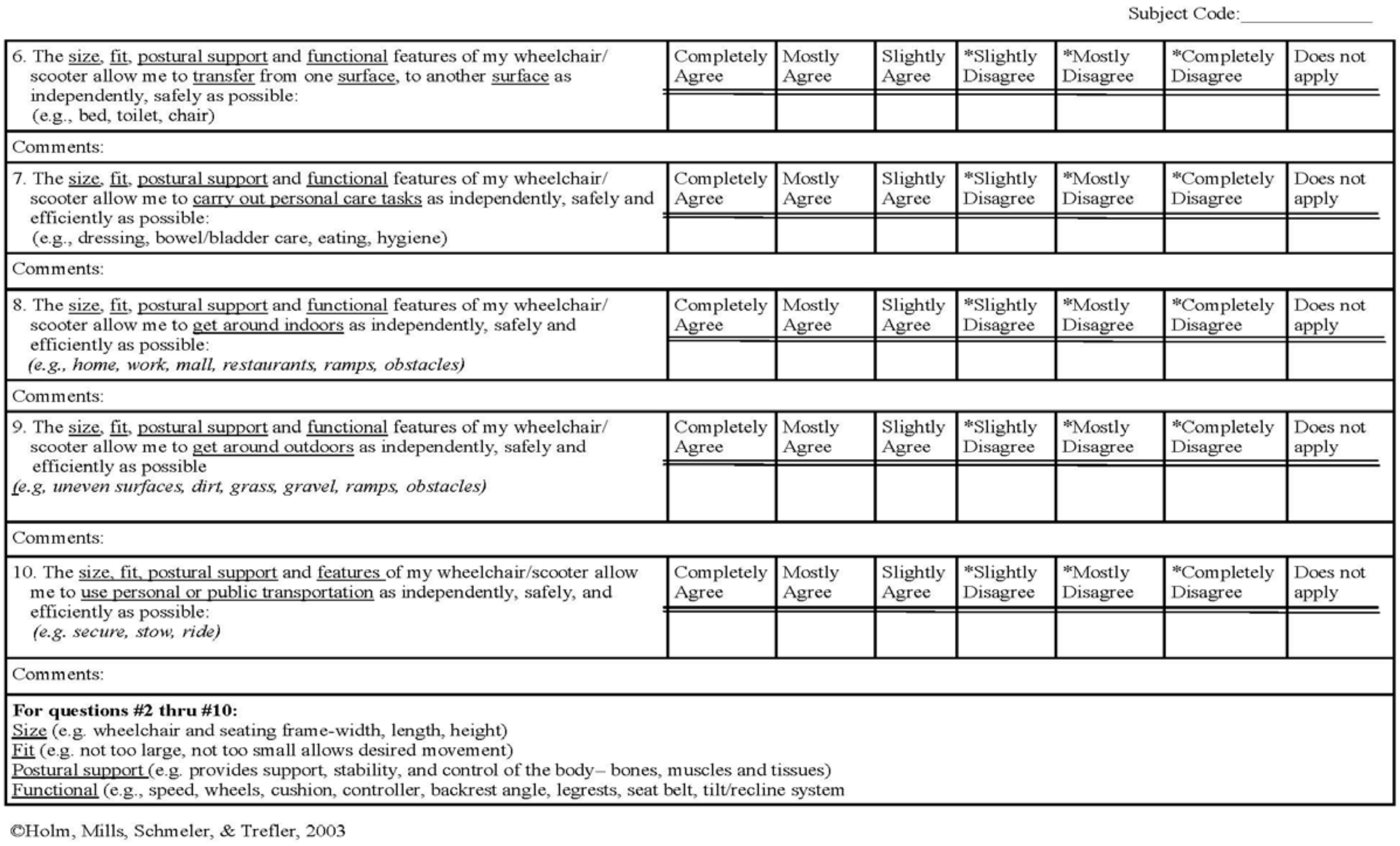
Subject Code:____________

Functioning Everyday with a Wheelchair (FEW)

DIRECTIONS: Please answer the following 10 questions by placing an "X" in the box under the response (completely agree, mostly agree, slightly agree, etc) that best matches your ability to function while in your wheelchair/scooter. All examples may not apply to you, and there may be tasks you perform that are not listed. Mark each question only one time. If you answer, "slightly, mostly, or completely disagree for any question, please circle the feature(s) (i.e., size, fit, postural support, functional) contribute g to your disagreement and write the reason for your disagreement in the comments section.

1. The stability, durability and dependability features of my wheelchair/scooter contribute to my ability to carry out my daily routines as independently, safely and efficiently as possible: *(e.g.. Tasks I want to do, need to do, am required to do-when and where needed.)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							
2. The size, fit, postural support and functional features of my wheelchair/scooter match my comfort needs as I carry out my daily routines: *(e.g. heat/moisture, sitting tolerance, pain , stability)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							
3. The size, fit, posture and functional features of my wheelchair/scooter match my health needs *(e.g., pressure sores, breathing, edema control, medical equipment)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							
4. The size, fit, postural support and functional features of my wheelchair/scooter allow me to operate it as independently, safely, and efficiently as possible: *(e.g, do what I want it to do when and where I want to do it.)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							
5. The size, fit, postural support and features of my wheelchair/scooter allow me to reach and carry out tasks at different surface heights as independently, safely, and efficiently as possible: *(e.g. table, counters, floors, shelves)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							

For questions #2 thru #10:
Size (e.g. wheelchair and seating frame-width, length, height)
Fit (e.g. not too large, not too small allows desired movement)
Postural support (e.g. provides support, stability, and control of the body– bones, muscles and tissues)
Functional (e.g., speed, wheels, cushion, controller, backrest angle, legrests, seat belt, tilt/recline system



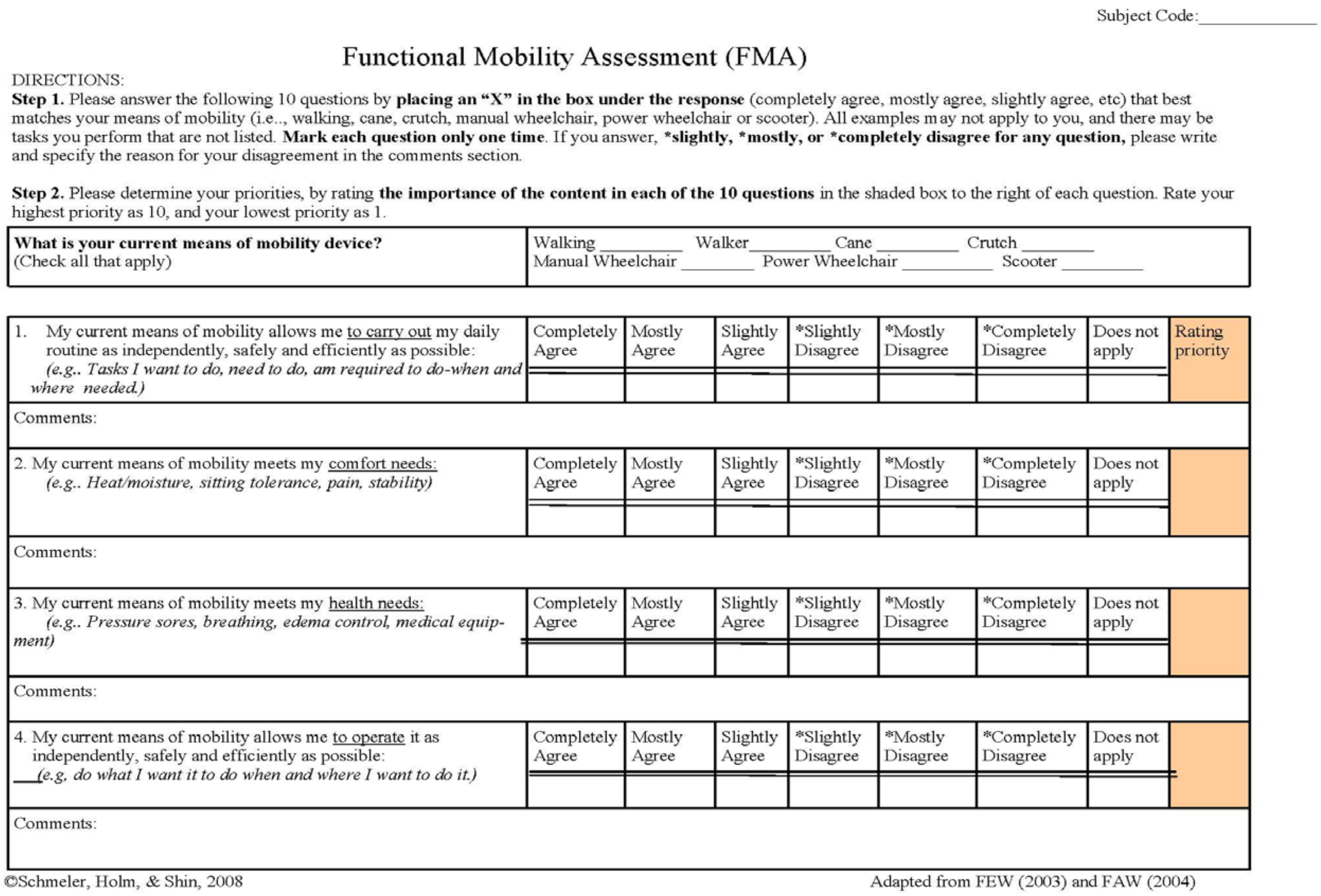
Subject Code:______________

6. The size, fit, postural support and functional features of my wheelchair/ scooter allow me to transfer from one surface, to another surface as independently, safely as possible: (e.g., bed, toilet, chair)	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							
7. The size, fit, postural support and functional features of my wheelchair/ scooter allow me to carry out personal care tasks as independently, safely and efficiently as possible: (e.g., dressing, bowel/bladder care, eating, hygiene)	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							
8. The size, fit, postural support and functional features of my wheelchair/ scooter allow me to get around indoors as independently, safely and efficiently as possible: *(e.g., home, work, mall, restaurants, ramps, obstacles)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							
9. The size, fit, postural support and functional features of my wheelchair/ scooter allow me to get around outdoors as independently, safely and efficiently as possible *(e.g, uneven surfaces, dirt, grass, gravel, ramps, obstacles)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							
10. The size, fit, postural support and features of my wheelchair/scooter allow me to use personal or public transportation as independently, safely, and efficiently as possible: *(e.g. secure, stow, ride)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:							

For questions #2 thru #10:
Size (e.g. wheelchair and seating frame-width, length, height)
Fit (e.g. not too large, not too small allows desired movement)
Postural support (e.g. provides support, stability, and control of the body– bones, muscles and tissues)
Functional (e.g., speed, wheels, cushion, controller, backrest angle, legrests, seat belt, tilt/recline system

APPENDIX B

FUNCTIONAL MOBILITY ASSESSMENT (FMA)



Subject Code:____________

Functional Mobility Assessment (FMA)

DIRECTIONS:

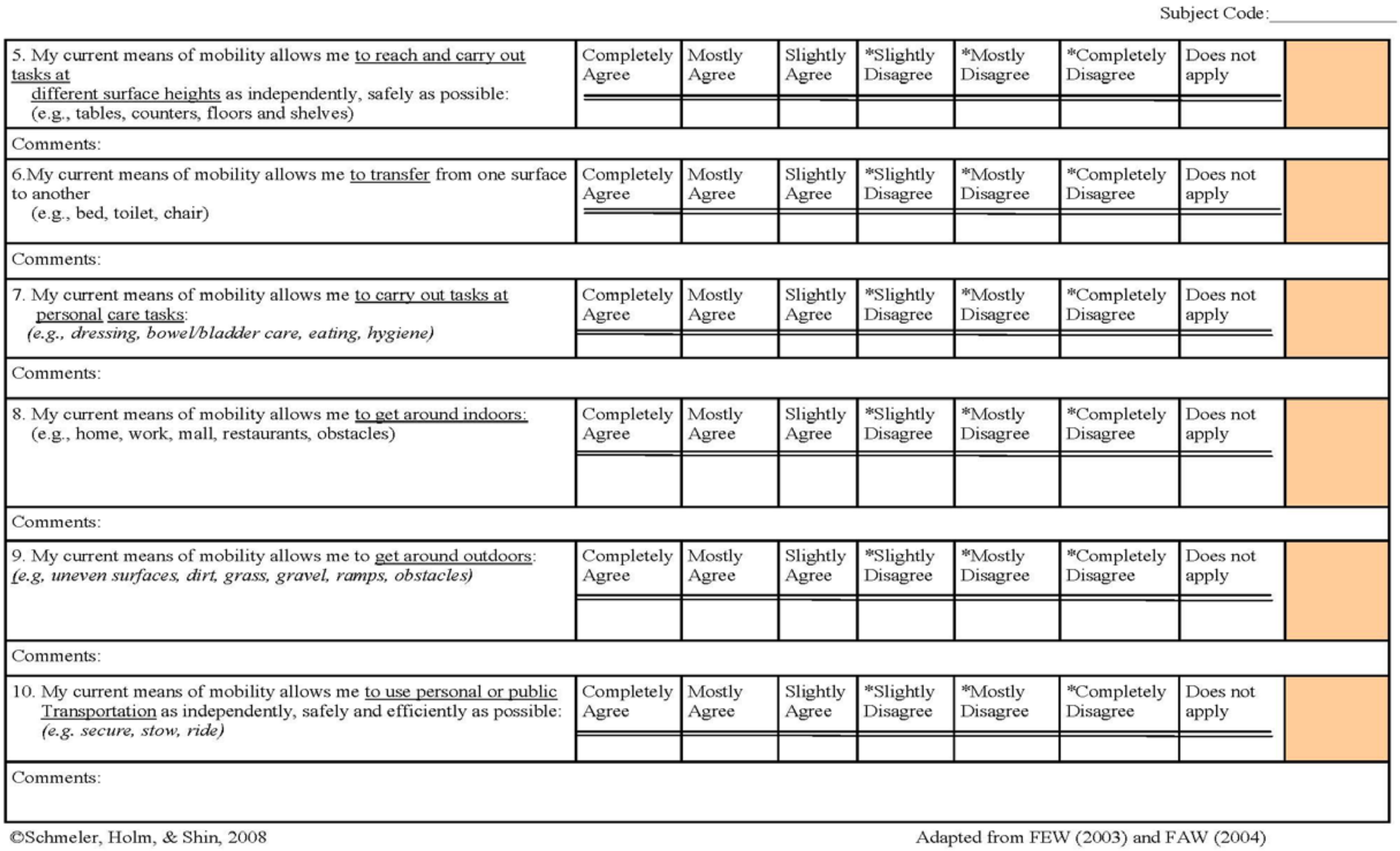
Step 1. Please answer the following 10 questions by **placing an "X" in the box under the response** (completely agree, mostly agree, slightly agree, etc) that best matches your means of mobility (i.e.., walking, cane, crutch, manual wheelchair, power wheelchair or scooter). All examples may not apply to you, and there may be tasks you perform that are not listed. **Mark each question only one time**. If you answer, ***slightly, *mostly, or *completely disagree for any question,** please write and specify the reason for your disagreement in the comments section.

Step 2. Please determine your priorities, by rating **the importance of the content in each of the 10 questions** in the shaded box to the right of each question. Rate your highest priority as 10, and your lowest priority as 1.

What is your current means of mobility device? (Check all that apply)	Walking ________ Walker________ Cane ________ Crutch ________ Manual Wheelchair ________ Power Wheelchair ________ Scooter ________

1. My current means of mobility allows me <u>to carry out</u> my daily routine as independently, safely and efficiently as possible: *(e.g.. Tasks I want to do, need to do, am required to do-when and where needed.)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	Rating priority
Comments:								
2. My current means of mobility meets my <u>comfort needs:</u> *(e.g.. Heat/moisture, sitting tolerance, pain, stability)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
Comments:								
3. My current means of mobility meets my <u>health needs:</u> *(e.g.. Pressure sores, breathing, edema control, medical equipment)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
Comments:								
4. My current means of mobility allows me <u>to operate</u> it as independently, safely and efficiently as possible: *(e.g, do what I want it to do when and where I want to do it.)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
Comments:								

Adapted from FEW (2003) and FAW (2004)



Subject Code:_______________

5. My current means of mobility allows me to reach and carry out tasks at different surface heights as independently, safely as possible: (e.g., tables, counters, floors and shelves)	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
Comments:								
6.My current means of mobility allows me to transfer from one surface to another (e.g., bed, toilet, chair)	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
Comments:								
7. My current means of mobility allows me to carry out tasks at personal care tasks: *(e.g., dressing, bowel/bladder care, eating, hygiene)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
Comments:								
8. My current means of mobility allows me to get around indoors: (e.g., home, work, mall, restaurants, obstacles)	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
Comments:								
9. My current means of mobility allows me to get around outdoors: *(e.g, uneven surfaces, dirt, grass, gravel, ramps, obstacles)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
Comments:								
10. My current means of mobility allows me to use personal or public Transportation as independently, safely and efficiently as possible: *(e.g. secure, stow, ride)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
Comments:								

Adapted from FEW (2003) and FAW (2004)

FUNCTIONAL MOBILITY ASSESSMENT –FMA

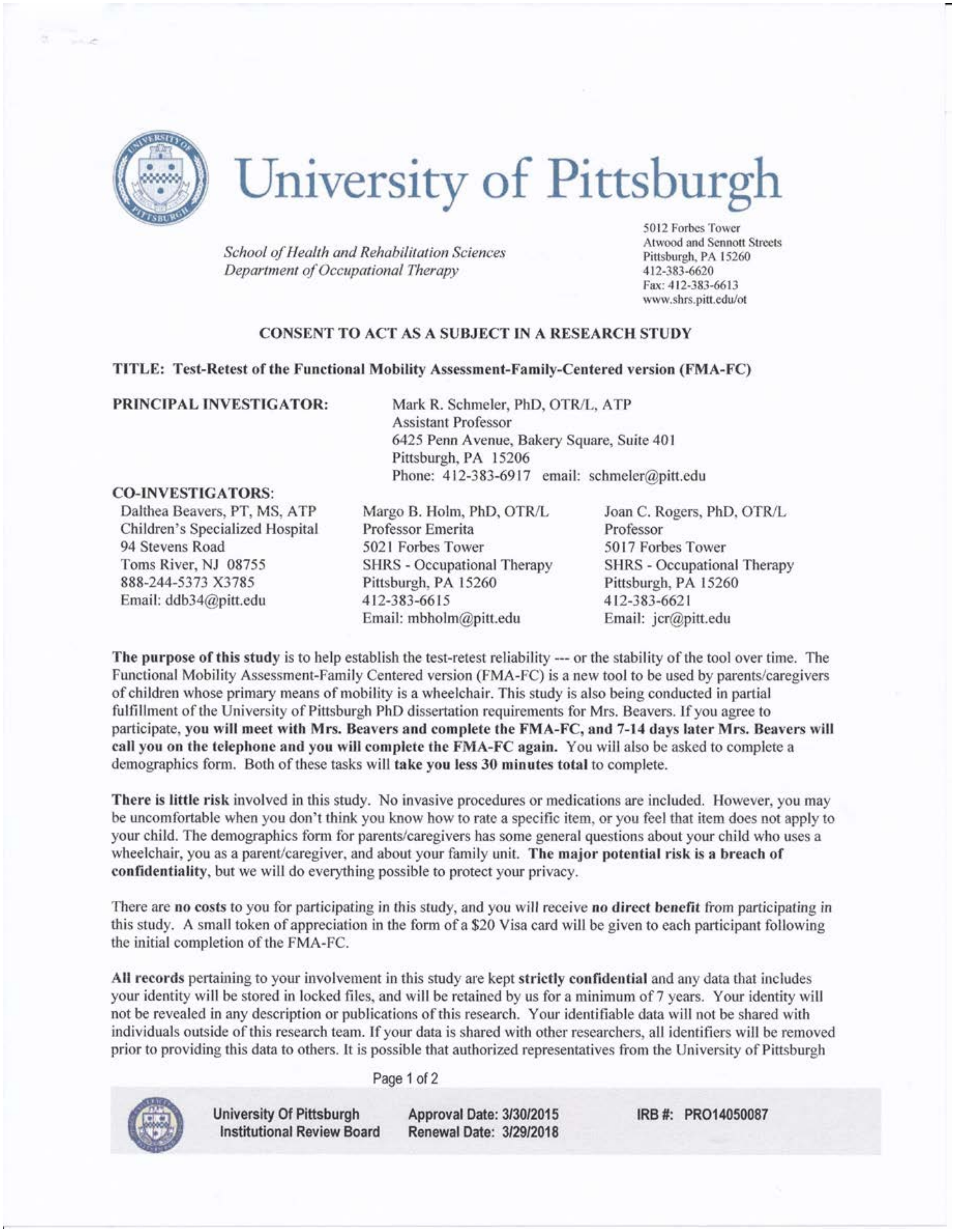
Scoring Scale for Client Responses

Percentage	Description	Score
100%	COMPLETELY AGREE	6
80%	MOSTLY AGREE	5
60%	SLIGHTLY AGREE	4
40%	SLIGHTLY DISAGREE	3
20%	MOSTLY DISAGREE	2
0%	COMPLETELY DISAGREE	1

Adapted from FEW (2003) and FAW (2004)

APPENDIX C

INSTITUTIONAL REVIEW BOARD APPROVED TEST-RETEST CONSENT FORM



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CONSENT TO ACT AS A SUBJECT IN A RESEARCH STUDY

TITLE: Test-Retest of the Functional Mobility Assessment-Family-Centered version (FMA-FC)

PRINCIPAL INVESTIGATOR:

Mark R. Schmeler, PhD, OTR/L, ATP
Assistant Professor
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The purpose of this study is to help establish the test-retest reliability --- or the stability of the tool over time. The Functional Mobility Assessment-Family Centered version (FMA-FC) is a new tool to be used by parents/caregivers of children whose primary means of mobility is a wheelchair. This study is also being conducted in partial fulfillment of the University of Pittsburgh PhD dissertation requirements for Mrs. Beavers. If you agree to participate, **you will meet with Mrs. Beavers and complete the FMA-FC, and 7-14 days later Mrs. Beavers will call you on the telephone and you will complete the FMA-FC again.** You will also be asked to complete a demographics form. Both of these tasks will **take you less 30 minutes total** to complete.

There is little risk involved in this study. No invasive procedures or medications are included. However, you may be uncomfortable when you don't think you know how to rate a specific item, or you feel that item does not apply to your child. The demographics form for parents/caregivers has some general questions about your child who uses a wheelchair, you as a parent/caregiver, and about your family unit. **The major potential risk is a breach of confidentiality**, but we will do everything possible to protect your privacy.

There are **no costs** to you for participating in this study, and you will receive **no direct benefit** from participating in this study. A small token of appreciation in the form of a $20 Visa card will be given to each participant following the initial completion of the FMA-FC.

All records pertaining to your involvement in this study are kept **strictly confidential** and any data that includes your identity will be stored in locked files, and will be retained by us for a minimum of 7 years. Your identity will not be revealed in any description or publications of this research. Your identifiable data will not be shared with individuals outside of this research team. If your data is shared with other researchers, all identifiers will be removed prior to providing this data to others. It is possible that authorized representatives from the University of Pittsburgh

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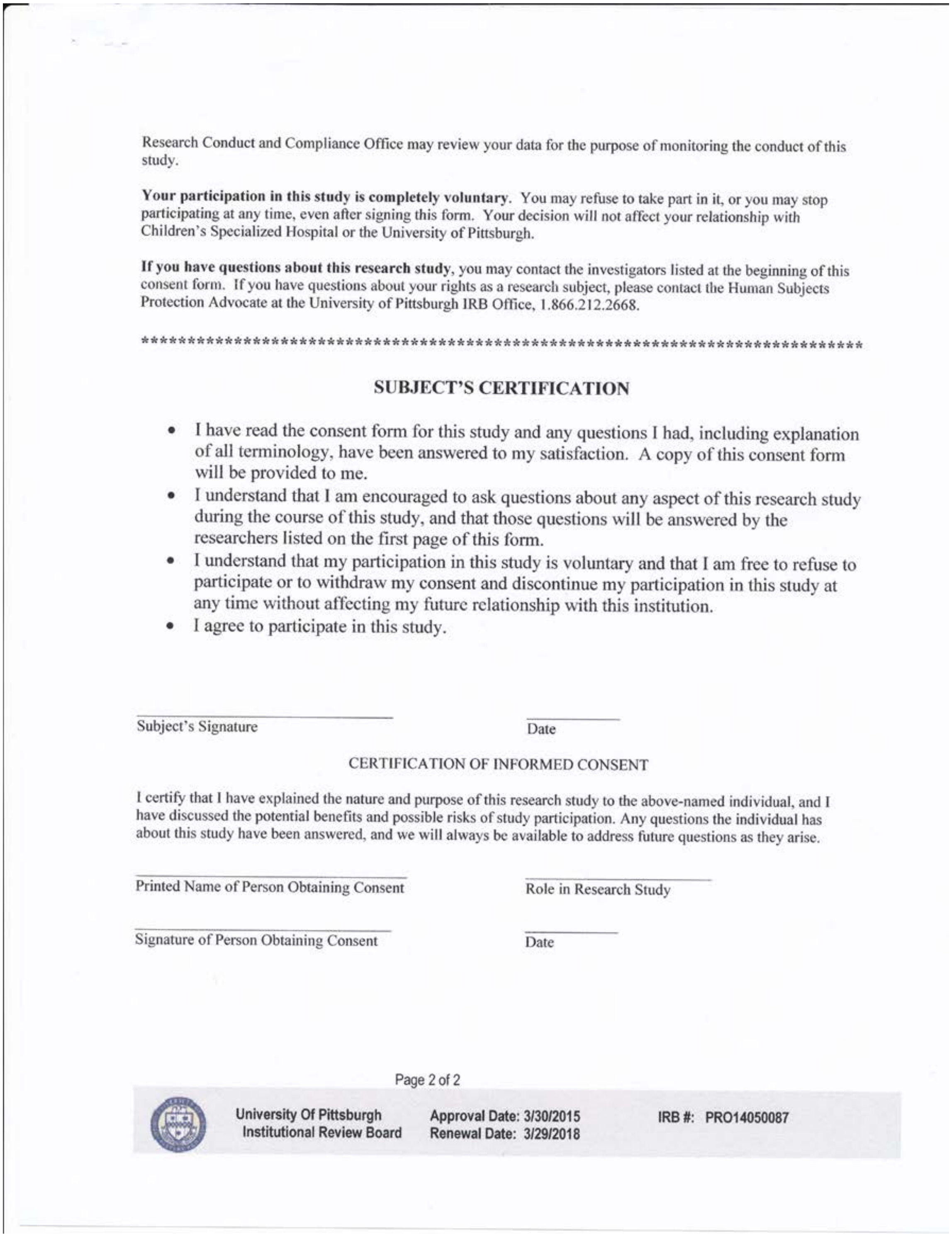
University Of Pittsburgh Institutional Review Board **Approval Date: 3/30/2015** **Renewal Date: 3/29/2018** **IRB #: PRO14050087**



Research Conduct and Compliance Office may review your data for the purpose of monitoring the conduct of this study.

Your participation in this study is completely voluntary. You may refuse to take part in it, or you may stop participating at any time, even after signing this form. Your decision will not affect your relationship with Children's Specialized Hospital or the University of Pittsburgh.

If you have questions about this research study, you may contact the investigators listed at the beginning of this consent form. If you have questions about your rights as a research subject, please contact the Human Subjects Protection Advocate at the University of Pittsburgh IRB Office, 1.866.212.2668.

****

SUBJECT'S CERTIFICATION

- I have read the consent form for this study and any questions I had, including explanation of all terminology, have been answered to my satisfaction. A copy of this consent form will be provided to me.
- I understand that I am encouraged to ask questions about any aspect of this research study during the course of this study, and that those questions will be answered by the researchers listed on the first page of this form.
- I understand that my participation in this study is voluntary and that I am free to refuse to participate or to withdraw my consent and discontinue my participation in this study at any time without affecting my future relationship with this institution.
- I agree to participate in this study.

Subject's Signature	Date

CERTIFICATION OF INFORMED CONSENT

I certify that I have explained the nature and purpose of this research study to the above-named individual, and I have discussed the potential benefits and possible risks of study participation. Any questions the individual has about this study have been answered, and we will always be available to address future questions as they arise.

Printed Name of Person Obtaining Consent	Role in Research Study
Signature of Person Obtaining Consent	Date

Page 2 of 2

University Of Pittsburgh
Institutional Review Board

Approval Date: 3/30/2015
Renewal Date: 3/29/2018

IRB #: PRO14050087

APPENDIX D

FUNCTIONAL MOBILITY ASSESSMENT - FAMILTY CENTERED (FMA-FC)

Beta-Version 1

Subject Code: _______

Functional Mobility Assessment – Family Centered version (FMA-FC)

DIRECTIONS:

STEP 1: Please answer the following 10 questions by **circling the words** (completely agree, mostly agree, etc.) or circling the percent of agreement (100%, 80%, etc.) that best matches your child's ability to function in his/her wheelchair. All examples may not apply to your child, and there may be tasks you perform that are not listed. **Mark each question only one time.** If you answer, ***slightly, *mostly, or *completely disagree – or answer 40%, 20% or 0% for any question, please write and specify the reason for your disagreement in the *Comments* section.**

STEP 2: Please determine your priorities, by rating **the importance of the content in each of the 10 questions for your child** in the shaded box to the right of each question. Rate your family's highest priority for your child as "10" and the lowest priority as "1."

What percent of time does your child use the following means of mobility each day: Walking____% Crawling_____% Cane_____% Walker_____%
Scooter______% Manual wheelchair_____% Power wheelchair_____% Stroller_____%

1. My child's current means of mobility allows our family <u>to carry out</u> our daily routines as independently, safely and efficiently as possible: *(e.g., tasks we want to do, need to do, are required to do- when and where needed)*	**Completely Agree** **100%**	**Mostly Agree** **80%**	**Slightly Agree** **60%**	***Slightly Disagree** **40%**	***Mostly Disagree** **20%**	***Completely Disagree** **0%**	**Does not apply**	**Rating priority**
Comments:								
2. My child's current means of mobility meets his/her <u>comfort needs</u>: *(e.g., heat/moisture, sitting tolerance, pain, stability)*	**Completely Agree** **100%**	**Mostly Agree** **80%**	**Slightly Agree** **60%**	***Slightly Disagree** **40%**	***Mostly Disagree** **20%**	***Completely Disagree** **0%**	**Does not apply**	
Comments:								
3. My child's current means of mobility meets his/her <u>health needs</u>: *(e.g., pressure sores, breathing, edema control, medical equipment)*	**Completely Agree** **100%**	**Mostly Agree** **80%**	**Slightly Agree** **60%**	***Slightly Disagree** **40%**	***Mostly Disagree** **20%**	***Completely Disagree** **0%**	**Does not apply**	
Comments:								
4. My child's current means of mobility allows him/her <u>to operate</u> as independently, safely and efficiently as possible: *(e.g., do what (s)he wants it to do when and where (s)he wants to do it)*	**Completely Agree** **100%**	**Mostly Agree** **80%**	**Slightly Agree** **60%**	***Slightly Disagree** **40%**	***Mostly Disagree** **20%**	***Completely Disagree** **0%**	**Does not apply**	
Comments:								

Adapted from FEW (2003), FAW (2004) and FMA (2008)

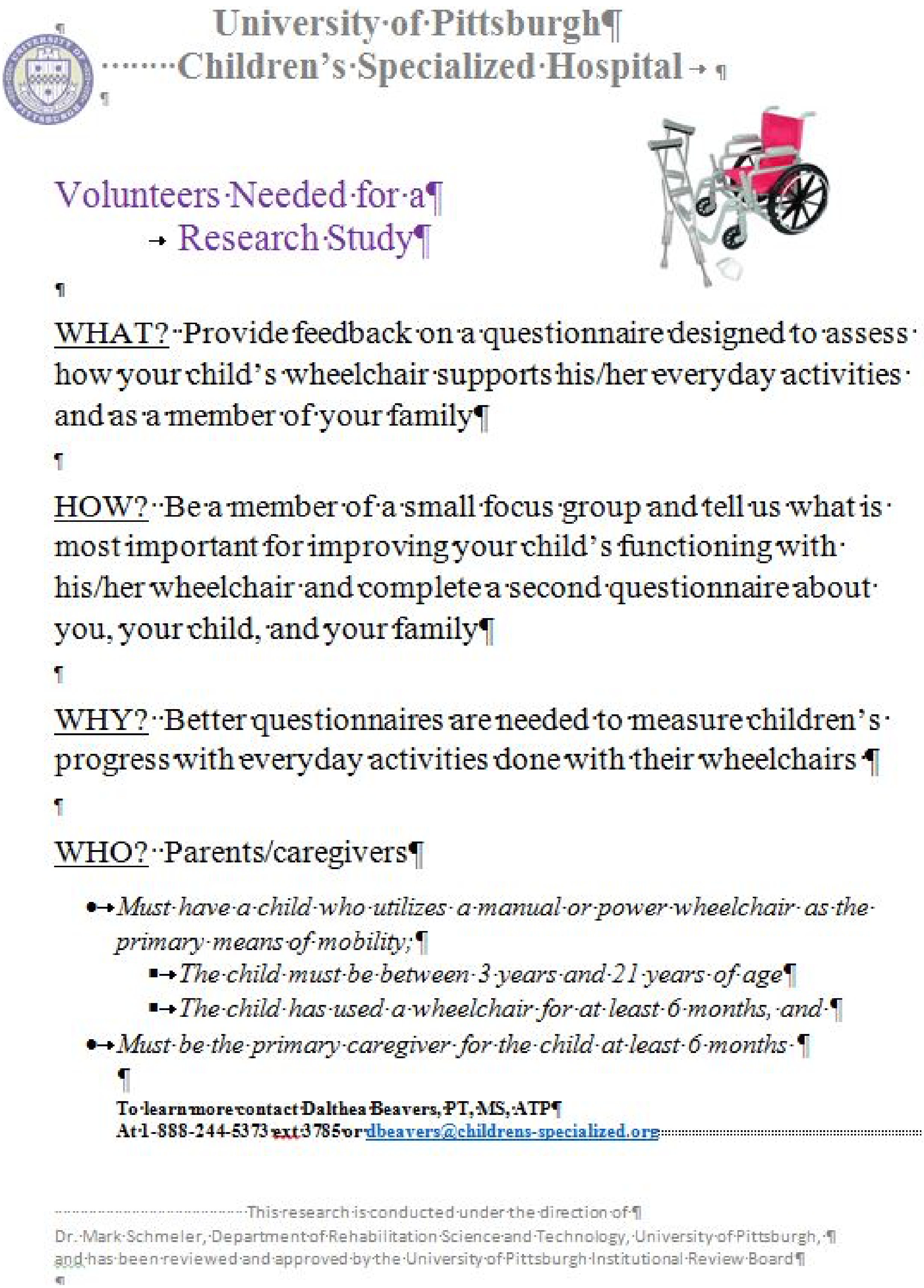
Subject Code: _______

5. My child's current means of mobility allows him/her to reach and carry out tasks at different surface heights as independently, safely and efficiently as possible: *(e.g., tables, desks, counters, floors, shelves)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	
Comments:								
6. My child's current means of mobility allows him/her to transfer from one surface to another: *(e.g., bed, toilet, chair, floor)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	
Comments:								
7. My child's current means of mobility allows him/her to carry out personal care tasks: *(e.g., dressing, bowel/bladder care, eating, hygiene)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	
Comments:								
8. My child's current means of mobility allows him/her to get around indoors: *(e.g., home, school, church, mall, restaurants, ramps, obstacles)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	
Comments:								
9. My child's current means of mobility allows him/her to get around outdoors: *(e.g., uneven surfaces, dirt, grass, gravel, ramps, obstacles)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	
Comments:								
10. My child's current means of mobility allows him/her to use personal (family car/van) or public transportation as independently, safely and efficiently as possible: *(e.g., secure, stow, ride)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	
Comments:								

Adapted from FEW (2003), FAW (2004) and FMA (2008)

APPENDIX E

PARENT/CAREGIVER FLYER



University of Pittsburgh
Children's Specialized Hospital

Volunteers Needed for a Research Study

WHAT? Provide feedback on a questionnaire designed to assess how your child's wheelchair supports his/her everyday activities and as a member of your family

HOW? Be a member of a small focus group and tell us what is most important for improving your child's functioning with his/her wheelchair and complete a second questionnaire about you, your child, and your family

WHY? Better questionnaires are needed to measure children's progress with everyday activities done with their wheelchairs

WHO? Parents/caregivers

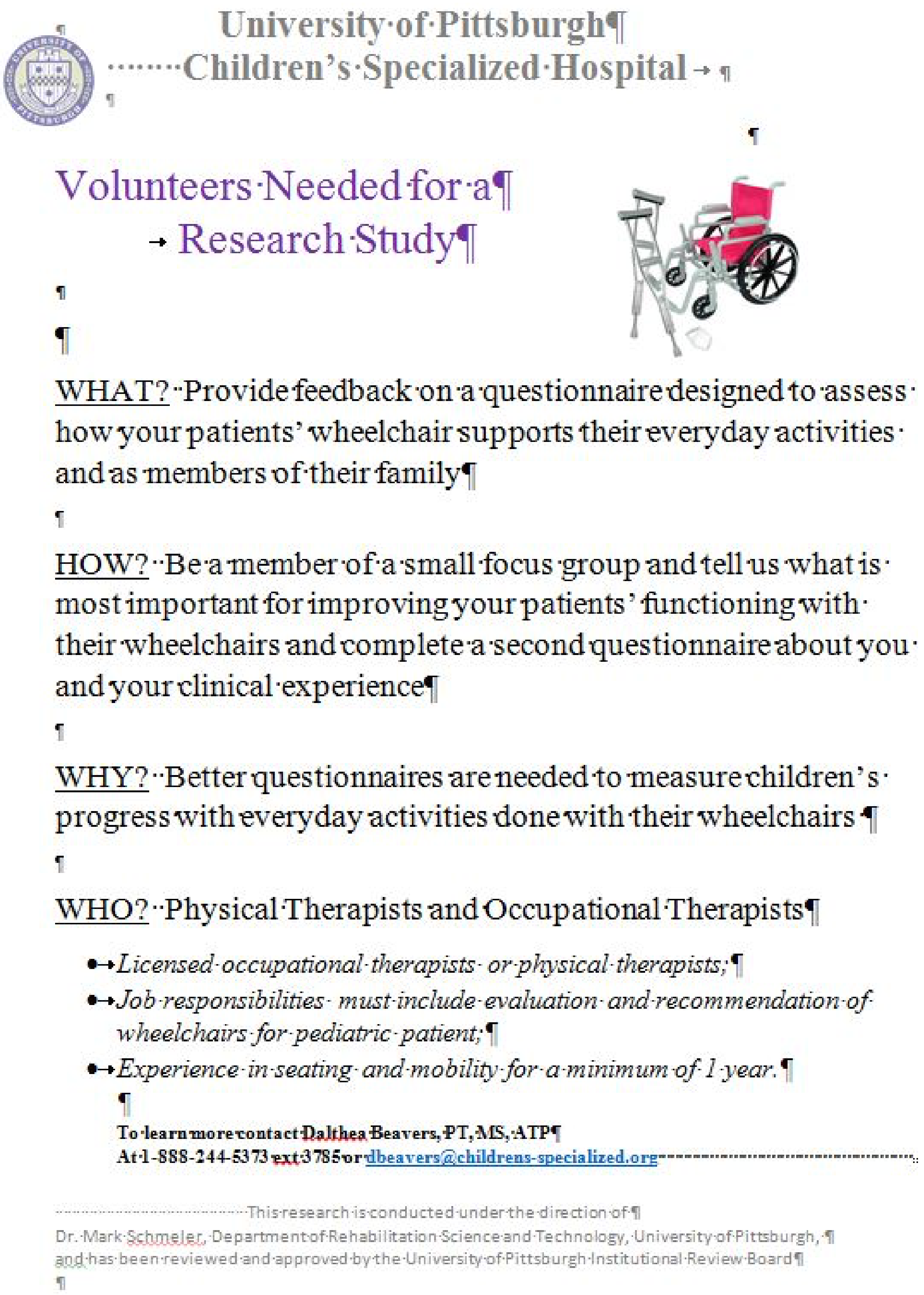
- *Must have a child who utilizes a manual or power wheelchair as the primary means of mobility;*
    - *The child must be between 3 years and 21 years of age*
    - *The child has used a wheelchair for at least 6 months, and*
- *Must be the primary caregiver for the child at least 6 months*

To learn more contact Dalthea Beavers, PT, MS, ATP
At 1-888-244-5373 ext 3785 or dbeavers@childrens-specialized.org

This research is conducted under the direction of
Dr. Mark Schmeler, Department of Rehabilitation Science and Technology, University of Pittsburgh,
and has been reviewed and approved by the University of Pittsburgh Institutional Review Board

APPENDIX F

THERAPIST FLYER



University of Pittsburgh
Children's Specialized Hospital

Volunteers Needed for a
Research Study

<u>WHAT?</u> Provide feedback on a questionnaire designed to assess how your patients' wheelchair supports their everyday activities and as members of their family

<u>HOW?</u> Be a member of a small focus group and tell us what is most important for improving your patients' functioning with their wheelchairs and complete a second questionnaire about you and your clinical experience

<u>WHY?</u> Better questionnaires are needed to measure children's progress with everyday activities done with their wheelchairs

<u>WHO?</u> Physical Therapists and Occupational Therapists

- *Licensed occupational therapists or physical therapists;*
- *Job responsibilities must include evaluation and recommendation of wheelchairs for pediatric patient;*
- *Experience in seating and mobility for a minimum of 1 year.*

To learn more contact Dalthea Beavers, PT, MS, ATP
At 1-888-244-5373 ext 3785 or dbeavers@childrens-specialized.org

This research is conducted under the direction of
Dr. Mark Schmeler, Department of Rehabilitation Science and Technology, University of Pittsburgh,
and has been reviewed and approved by the University of Pittsburgh Institutional Review Board

APPENDIX G

PARENT/CAREGIVER DEMOGRAPHICS FORM

IRB Stamp Validation

University of Pittsburgh
Children's Specialized Hospital

Children's Specialized Hospital

Parent/Caregiver Demographics

Your Child with mobility impairment	You	Your family
How old is your child with special needs?	What is your age? ☐ 19 or younger ☐ 20-30 ☐ 31-40 ☐ 41-50 ☐ 51-60 ☐ 61+	How many people in your family?
What is his/her diagnosis?	Do you have a disability?	If you have other children where does your child with special needs fall in the order age-wise?
Is your child generally healthy?	Are you generally healthy?	How is the general health of your family?
If not, which system/systems is/are most involved with your child? ☐ Respiratory ☐ Musculoskeletal ☐ Neuromuscular ☐ Cardiac	If not, which of your system/ systems is/are involved? ☐ Respiratory ☐ Musculoskeletal ☐ Neuromuscular ☐ Cardiac	If not, which of their system/systems is/are involved? ☐ Respiratory ☐ Musculoskeletal ☐ Neuromuscular ☐ Cardiac
What mobility equipment does he/she have?	What do you like about your child's mobility device?	What type of vehicle do you transport your child?
How much assistance does he/she need for transfers?	What don't you like about your child's mobility device?	Is your vehicle equipped with WTORS?
Average time your child spends using his/her mobility device?	What was important to you when your child was evaluated for his/her mobility device? ☐ Postural support ☐ Mobility ☐ Transportability ☐ Independence	Does the wheelchair allow your family to do what you want and need to do as a family unit?

APPENDIX H

SCRIPT FOR PARENTS/CAREGIVERS

SCRIPT FOR PARENT/CAREGIVER FOCUS GROUPS

Welcome,

For those of you that don't know me, My name is Dalthea Beavers. I am your moderator tonight. I also am a physical therapist at Children's Specialized Hospital. The development of this Family Centered Outcome Measure is my doctoral project with the University of Pittsburgh. We at Children's and Pitt thank you for agreeing to be part of this focus group.

I want to remind each of you that I am recording this session so that I can go back and review our discussion. You will also notice that on the tent card in front of you there is a number. Please refer to each other by number, and I will do the same, so that there are no names on the audiotape. Likewise, please do not refer to your child by name, but rather by "my child."

FIRST OF ALL, did you have an opportunity to review the draft of the Functional Mobility Assessment- Family Centered version of the new tool we are developing?

IF NOT, let me review the tool with you quickly. There are 10 items, and they are designed to ascertain the degree to which your children's wheelchairs support the everyday activities they want to do, need to do, and are expected to do….within and outside of the family. For each item you are asked to give your level of agreement with the statement….For example, Completely Agree (100% agreement), or Mostly Agree (80% agreement), etc.

ANY QUESTIONS YET?

NEXT….WHAT IS IMPORTANT TO YOU, YOUR CHILD AND YOUR FAMILY WHEN CONSIDERING THE TYPE OF SUPPORT YOU WANT A WHEELCHAIR TO PROVIDE FOR YOUR CHILD…AND FOR WHICH ACTIVITIES?

(probes = anything else?, other ideas? anyone have other suggestions?)

NEXT…..WHAT ACTIVITIES/ ITEMS SHOULD BE ADDED TO THE DRAFT?

(probes = anything else?, other ideas? anyone have other suggestions?)

NEXT…..ARE THERE ANY SUGGESTIONS ABOUT ITEMS THAT SHOULD BE MODIFIED?

(WORDING CHANGES/ EMPHASIS CHANGED?)

(probes = anything else?, other ideas? anyone have other suggestions?)

THE TYPE OF SUPPORT YOU WANT A WHEELCHAIR TO PROVIDE FOR YOUR CHILD...AND FOR WHICH ACTIVITIES?

(probes = anything else?, other ideas? anyone have other suggestions?)

NEXT.....WHAT ACTIVITIES/ ITEMS SHOULD BE ADDED TO THE DRAFT?

(probes = anything else?, other Ideas? anyone have other suggestions?)

NEXT.....ARE THERE ANY SUGGESTIONS ABOUT ITEMS THAT SHOULD BE MODIFIED?

(WORDING CHANGES/ EMPHASIS CHANGED?)

(probes = anything else?, other ideas? anyone have other suggestions?)

NEXT.....ARE THERE ANY ITEMS THAT SHOULD BE DELETED?

(probes = anything else?, other ideas? anyone have other suggestions?)

NOW I AM GOING TO ASK YOU TO RATE EACH OF THE ITEMS THAT ARE ON THE DRAFT COPY OF THE FMA-FC AND THE NEW ITEMS ON THE FLIP CHART...NO NAMES ON THE FORMS PLEASE....

PLEASE RATE EACH ITEM FOR

- RELEVANCE TO YOUR CHILD AND FAMILY
- CLARITY OF THE WORDING
- EASE OF RATING

I WILL NOW COLLECT THE RATING FORMS

THANK YOU VERY MUCH FOR PARTICIPATING IN THIS STUDY, AND I WOULD LIKE TO OFFER EACH OF YOU A $20 VISA CARD AS A TOKEN OF MY APPRECIATION FOR ASSISTING WITH THIS STUDY AND MY DISSERTATION.

APPENDIX I

FMA-FC ITEM RATING FORM

FMA-FC ITEM RATING FORM

ITEM #______________

RELEVANCE of the item for supporting what my child/patient wants to do, needs to do, and is expected to do from his/her wheelchair:

- ☐ Completely relevant
- ☐ Mostly relevant
- ☐ Slightly relevant
- ☐ Mostly irrelevant
- ☐ Completely irrelevant

CLARITY of the item for reflecting what my child/patient wants to do, needs to do, and is expected to do from his/her wheelchair:

- ☐ Completely clear
- ☐ Mostly clear
- ☐ Slightly clear
- ☐ Mostly unclear
- ☐ Completely unclear

EASE OF RATING this item using the scale provided

- ☐ Completely easy
- ☐ Mostly easy
- ☐ Slightly easy
- ☐ Mostly not easy
- ☐ Completely not easy

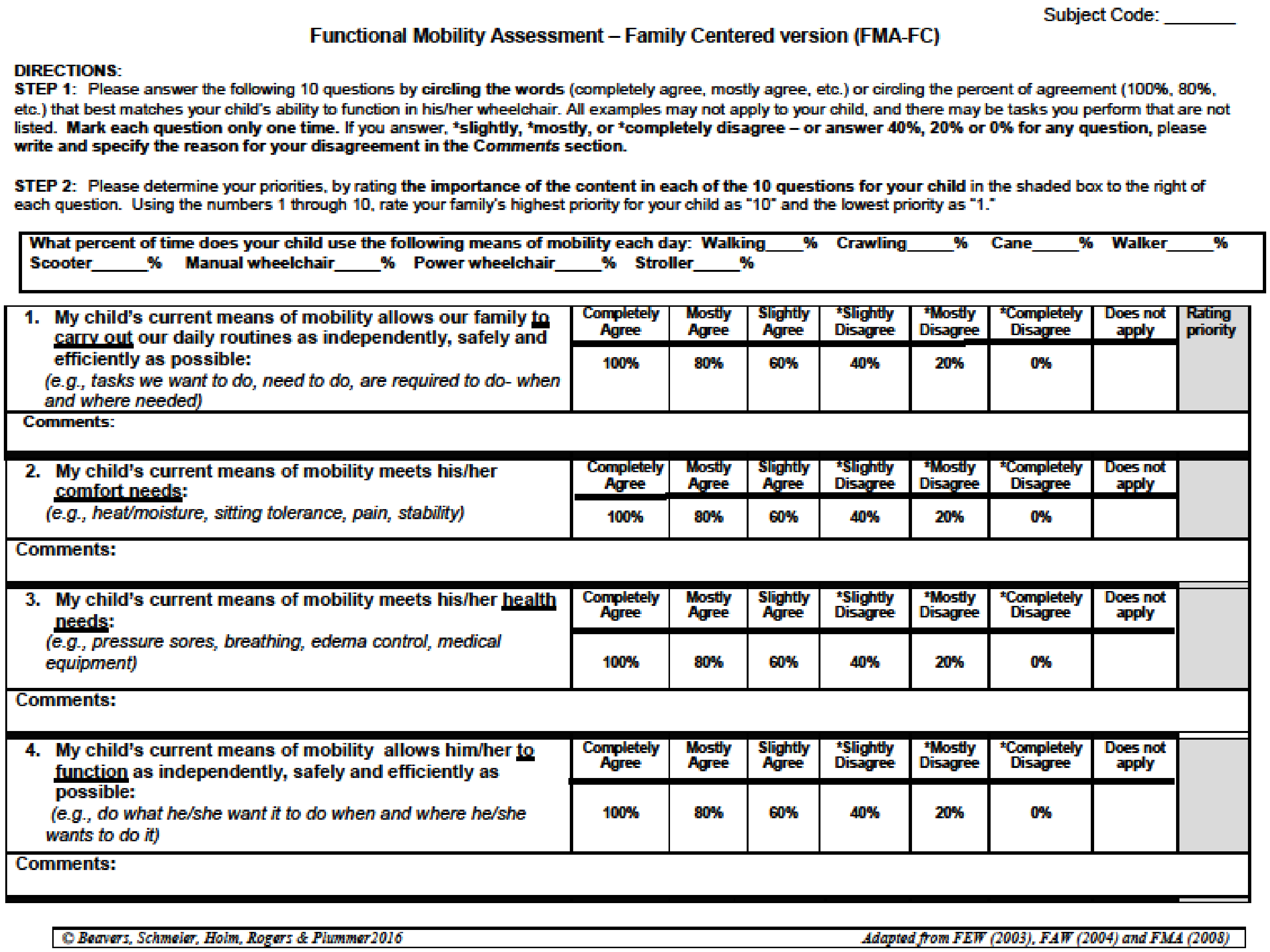
I RECOMMEND THAT THIS ITEM BE:

- ☐ Kept as it is
- ☐ Deleted
- ☐ Modified as follows:

APPENDIX J

FUNCTIONAL MOBILITY ASSESSMENT-FAMILY CENTERED (FMA-FC)

Beta-Version 2



Subject Code: _______

Functional Mobility Assessment – Family Centered version (FMA-FC)

DIRECTIONS:

STEP 1: Please answer the following 10 questions by **circling the words** (completely agree, mostly agree, etc.) or circling the percent of agreement (100%, 80%, etc.) that best matches your child's ability to function in his/her wheelchair. All examples may not apply to your child, and there may be tasks you perform that are not listed. **Mark each question only one time.** If you answer, ***slightly, *mostly, or *completely disagree – or answer 40%, 20% or 0% for any question,** please **write and specify the reason for your disagreement in the *Comments* section.**

STEP 2: Please determine your priorities, by rating **the importance of the content in each of the 10 questions for your child** in the shaded box to the right of each question. Using the numbers 1 through 10, rate your family's highest priority for your child as "10" and the lowest priority as "1."

What percent of time does your child use the following means of mobility each day: Walking____% Crawling_____% Cane_____% Walker_____% Scooter______% Manual wheelchair_____% Power wheelchair_____% Stroller_____%

1. My child's current means of mobility allows our family <u>to carry out</u> our daily routines as independently, safely and efficiently as possible: *(e.g., tasks we want to do, need to do, are required to do- when and where needed)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	Rating priority
	100%	80%	60%	40%	20%	0%		
Comments:								
2. My child's current means of mobility meets his/her <u>comfort needs</u>: *(e.g., heat/moisture, sitting tolerance, pain, stability)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
	100%	80%	60%	40%	20%	0%		
Comments:								
3. My child's current means of mobility meets his/her <u>health needs</u>: *(e.g., pressure sores, breathing, edema control, medical equipment)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
	100%	80%	60%	40%	20%	0%		
Comments:								
4. My child's current means of mobility allows him/her <u>to function</u> as independently, safely and efficiently as possible: *(e.g., do what he/she want it to do when and where he/she wants to do it)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
	100%	80%	60%	40%	20%	0%		
Comments:								

© Beavers, Schmeler, Holm, Rogers & Plummer2016 *Adapted from FEW (2003), FAW (2004) and FMA (2008)*

Subject Code: _______

5. My child's current means of mobility allows him/her to reach and carry out tasks at different surface heights as independently, safely and efficiently as possible: *(e.g., table, counters, floors, shelves)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply
Comments:							
6. My child's current means of mobility allows him/her to transfer from one surface to another: *(e.g., bed, toilet, chair)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply
Comments:							
7. My child's current means of mobility allows him/her to carry out personal care tasks: *(e.g., dressing, bowel/bladder care, eating, hygiene)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply
Comments:							
8. My child's current means of mobility allows him/her to get around indoors AND outdoors: *(e.g., indoors = home, school, mall, restaurants – outdoors = uneven surfaces, grass, gravel, ramps, obstacles)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply
Comments:							
9. My child's current means of mobility allows him/her to socialize with other children independent of family caregiver: *(e.g., mobility device accepted by other children; raises eye level to that of other children for easier socialization)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply
Comments:							
10. My child's current means of mobility allows him/her to use school, personal or public transportation as independently, safely and efficiently as possible: *(e.g., secure, stow, ride)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply
Comments:							

Adapted from FEW (2003), FAW (2004) and FMA (2008)

APPENDIX K

THERAPIST DEMOGRAPHICS FORM

IRB Stamp Validation

University of Pittsburgh
Children's Specialized Hospital

Children's Specialized Hospital

Therapist Demographics

Discipline	☐ OT ☐ PT	
How long have you practiced?	_______________ years	
How long have you prescribed WMDs?	_______________ years	
What is your WMD caseload per month?	_______________	
Type of problems necessitating a WMD?	1.	2.
	3.	4.
	5.	6.
How involved are most of the families in the decision-making process for the WMD?	☐ Not at all involved ☐ Somewhat involved ☐ Very involved	
Age ranges of your patients?	☐ younger than 3 years ☐ 3-6 years ☐ 7-12 years ☐ 13-18 years	

APPENDIX L

SCRIPT FOR THERAPISTS

SCRIPT FOR THERAPIST FOCUS GROUPS

Welcome,

For those of you that don't know me, My name is Dalthea Beavers. I am your moderator tonight. I also am a physical therapist at Children's Specialized Hospital. The development of this Family Centered Outcome Measure is my doctoral project with the University of Pittsburgh. We at Children's and Pitt thank you for agreeing to be part of this focus group.

I want to remind each of you that I am recording this session so that I can go back and review our discussion. You will also notice that on the tent card in front of you there is a number. Please refer to each other by number, and I will do the same, so that there are no names on the audiotape. Likewise, please do not refer to any patients by name when giving examples, but rather by "my patient."

FIRST OF ALL, did you have an opportunity to review the draft of the Functional Mobility Assessment- Family Centered version of the new tool we are developing?

IF NOT, let me review the tool with you quickly. There are 10 items, and they are designed to ascertain the degree to which your children's wheelchairs support the everyday activities they want to do, need to do, and are expected to do….within and outside of the family. For each item you are asked to give your level of agreement with the statement….For example, Completely Agree (100% agreement), or Mostly Agree (80% agreement), etc.

ANY QUESTIONS YET?

NEXT….WHAT DO YOU THINK IS IMPORTANT TO YOUR PATIENTS AND THEIR FAMILIES WHEN CONSIDERING THE TYPE OF SUPPORT YOU WANT A WHEELCHAIR TO PROVIDE FOR THE PATIENT…AND FOR WHICH ACTIVITIES?

(probes = anything else?, other ideas? anyone have other suggestions?)

NEXT…..WHAT ACTIVITIES/ ITEMS SHOULD BE ADDED TO THE DRAFT?

(probes = anything else?, other ideas? anyone have other suggestions?)

NEXT…..ARE THERE ANY SUGGESTIONS ABOUT ITEMS THAT SHOULD BE MODIFIED?

(WORDING CHANGES/ EMPHASIS CHANGED?)

CONSIDERING THE TYPE OF SUPPORT YOU WANT A WHEELCHAIR TO PROVIDE FOR THE PATIENT...AND FOR WHICH ACTIVITIES?

(probes = anything else?, other ideas? anyone have other suggestions?)

NEXT.....WHAT ACTIVITIES/ ITEMS SHOULD BE ADDED TO THE DRAFT?

(probes = anything else?, other ideas? anyone have other suggestions?)

NEXT.....ARE THERE ANY SUGGESTIONS ABOUT ITEMS THAT SHOULD BE MODIFIED?

(WORDING CHANGES/ EMPHASIS CHANGED?)

(probes = anything else?, other ideas? anyone have other suggestions?)

NEXT.....ARE THERE ANY ITEMS THAT SHOULD BE DELETED?

(probes = anything else?, other ideas? anyone have other suggestions?)

NOW I AM GOING TO ASK YOU TO RATE EACH OF THE ITEMS THAT ARE ON THE DRAFT COPY OF THE FMA-FC AND THE NEW ITEMS ON THE FLIP CHART...NO NAMES ON THE FORMS PLEASE....

PLEASE RATE EACH ITEM FOR

- RELEVANCE TO YOUR PATIENTS AND THEIR FAMILIES
- CLARITY OF THE WORDING
- EASE OF RATING

I WILL NOW COLLECT THE RATING FORMS

THANK YOU VERY MUCH FOR PARTICIPATING IN THIS STUDY, AND I WOULD LIKE TO OFFER EACH OF YOU A $20 VISA CARD AS A TOKEN OF MY APPRECIATION FOR ASSISTING WITH THIS STUDY AND MY DISSERTATION.

APPENDIX M

FUNCTIONAL MOBILITY ASSESSMENT - FAMILY CENTERED (FMA-FC)

Beta-version 3

Functional Mobility Assessment – Family Centered version (FMA-FC)

DIRECTIONS:
STEP 1: Please answer the following 10 questions by **circling the words** (completely agree, mostly agree, etc.) or circling the percent of agreement (100%, 80%, etc.) that best matches your child's ability to function in his/her wheelchair. All examples may not apply to your child, and there may be tasks you perform that are not listed. **Mark each question only one time.** If you answer, ***slightly, *mostly, or *completely disagree – or answer 40%, 20% or 0% for any question, please write and specify the reason for your disagreement in the C*omments* section.**

STEP 2: To determine your priorities, review the content of each of the 10 questions then choose the 3 most important questions. **Rate the importance of the content in those the 3 questions for your child** in the shaded box to the right of each question. Using the numbers 1 through 3, rate your family's highest priority for your child as "1" and the lowest priority as "3."

What percent of time does your child use the following means of mobility each day: Walking____% Crawling_____% Cane_____% Walker_____% Scooter______% Manual wheelchair_____% Power wheelchair_____% Stroller_____%

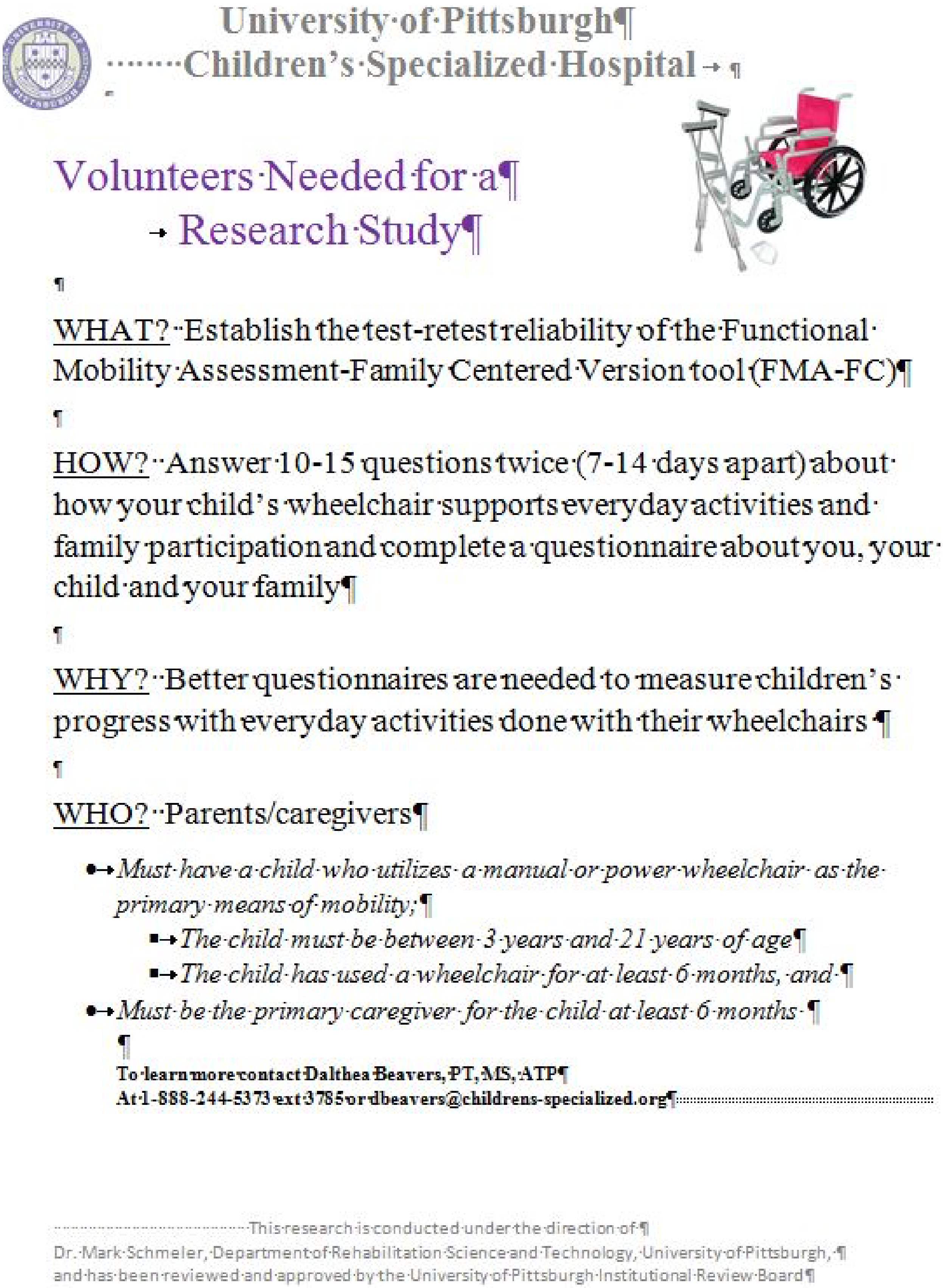
1. My child's current means of mobility allows our family to participate in our daily routines as independently, safely and as easily as possible: *(e.g., tasks we want to do, need to do, are required to do- when and where needed)*	**Completely Agree** **100%**	**Mostly Agree** **80%**	**Slightly Agree** **60%**	***Slightly Disagree** **40%**	***Mostly Disagree** **20%**	***Completely Disagree** **0%**	**Does not apply**	Rating priority
Comments:								
2. My child's current means of mobility meets his/her comfort needs: *(e.g., heat/moisture, ability to sit for a long time, pain free)*	**Completely Agree** **100%**	**Mostly Agree** **80%**	**Slightly Agree** **60%**	***Slightly Disagree** **40%**	***Mostly Disagree** **20%**	***Completely Disagree** **0%**	**Does not apply**	
Comments:								
3. My child's current means of mobility meets his/her postural support needs: *(e.g., no redness or sores on skin, good support for breathing, decreased or no swelling, maintain sitting balance while completing activities)*	**Completely Agree** **100%**	**Mostly Agree** **80%**	**Slightly Agree** **60%**	***Slightly Disagree** **40%**	***Mostly Disagree** **20%**	***Completely Disagree** **0%**	**Does not apply**	
Comments:								
4. My child's current means of mobility allows for managing his/her daily supplies: *(e.g., Medical – ventilator, oxygen, suction, catheter tubing)* *Personal – computer, braces, phone, lunch etc.)*	**Completely Agree** **100%**	**Mostly Agree** **80%**	**Slightly Agree** **60%**	***Slightly Disagree** **40%**	***Mostly Disagree** **20%**	***Completely Disagree** **0%**	**Does not apply**	
Comments:								

Adapted from FEW (2003), FAW (2004) and FMA (2008)

5. My child's current means of mobility allows him/her to access and complete tasks at different surface heights as independently, safely and easily as possible: *(e.g., get under desks, tables, counters, floors, shelves)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	Rating priority
	100%	80%	60%	40%	20%	0%		
Comments:								
6. My child's current means of mobility allows him/her to participate (with or without help) in transfers from one surface to another: *(e.g., bed, toilet, chair)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
	100%	80%	60%	40%	20%	0%		
Comments:								
7. My child's current means of mobility allows him/her to complete personal care tasks easily: *(e.g., dressing, toileting care, eating, washing, brushing teeth)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
	100%	80%	60%	40%	20%	0%		
Comments:								
8. My child's current means of mobility allows him/her to get around indoors AND outdoors: *(e.g., indoors = home, school, mall, restaurants – outdoors = playgrounds, uneven surfaces, grass, gravel, ramps, obstacles)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
	100%	80%	60%	40%	20%	0%		
Comments:								
9. My child's current means of mobility allows him/her to do what he/she wants to do independent of family/caregiver: *(e.g., socialize, provide Bluetooth accessibility, accessible to peers)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
	100%	80%	60%	40%	20%	0%		
Comments:								
10. My child's current means of mobility allows him/her to use school, personal or public transportation as independently, safely and easily as possible: *(e.g., secure, fold and store, ride)*	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
	100%	80%	60%	40%	20%	0%		
Comments:								

APPENDIX N

TEST-RETEST STUDY FLYER



University of Pittsburgh
Children's Specialized Hospital

Volunteers Needed for a Research Study

WHAT? Establish the test-retest reliability of the Functional Mobility Assessment-Family Centered Version tool (FMA-FC)

HOW? Answer 10-15 questions twice (7-14 days apart) about how your child's wheelchair supports everyday activities and family participation and complete a questionnaire about you, your child and your family

WHY? Better questionnaires are needed to measure children's progress with everyday activities done with their wheelchairs

WHO? Parents/caregivers

- *Must have a child who utilizes a manual or power wheelchair as the primary means of mobility;*
    - *The child must be between 3 years and 21 years of age*
    - *The child has used a wheelchair for at least 6 months, and*
- *Must be the primary caregiver for the child at least 6 months*

To learn more contact Dalthea Beavers, PT, MS, ATP
At 1-888-244-5373 ext 3785 or dbeavers@childrens-specialized.org

This research is conducted under the direction of
Dr. Mark Schmeler, Department of Rehabilitation Science and Technology, University of Pittsburgh,
and has been reviewed and approved by the University of Pittsburgh Institutional Review Board

APPENDIX O

SCRIPT FOR TEST-RETEST PARTICIPANTS

SCRIPT FOR TEST-RETEST PARENTS

Thank you for agreeing to talk to me about the Test-Retest study. My name is Dalthea Beavers. I am a physical therapist at Children's Specialized Hospital and the development of this Family Centered Outcome Measure is my doctoral project with the University of Pittsburgh.

FIRST OF ALL, let me explain the study to you to see if you want to participate. Here is a copy of the Consent Form so that you can follow along as I talk. For a measurement tool to be considered reliable, we need to test it. This is done by having parents/caregivers fill it out once, and then 7-14 days later fill it out again. There are only 10-15 questions, and they focus on how well your child's wheelchair supports him/her in the daily activities he/she wants to do, needs to do, or is expected to do.

[Review Consent Form page by page]

ARE YOU INTERESTED IN PARTICIPATING?

IF YES.....PROCEED TO HAVE THE PARENT/CAREGIVER SIGN THE CONSENT, AND THEN COMPLETE THE DEMOGRAPHIC FORM.

- **THEN COMPLETE AN APPOINTMENT FORM FOR THE TELEPHONE CALL.**
- **PROVIDE THE PARENT/CAREGIVER WITH A BLANK COPY OF THE FMA-FC TO REFER TO DURING THE TELEPHONE CALL.**

IF NO, THANK THEM FOR THEIR CONSIDERATION.

7-14 DAYS LATER......

HELLO MRS/MS./MR...................... THIS IS DALTHEA BEAVERS CALLING FOR OUR APPOINTMENT TO COMPLETE THE FMA-FC. DO YOU HAVE IT HANDY TO REFER TO?

IF NOT WAIT.....OR ASK IF IT IS BETTER TO CALL BACK.

OK....I WILL READ EACH ITEM TO YOU, AND YOU ANSWER WITH EITHER THE WORDS FOR YOUR LEVEL OF AGREEMENT OR THE PERCENT OF YOUR LEVEL OF AGREEMENT.

PROCEED TO COMPLETE THE RATING OF THE TOOL, CIRCLING EACH RESPONSE.

THANK YOU AGAIN MRS/MS/MR ____________ FOR PARTICIPATING IN THIS STUDY. I REALLY APPRECIATE THE TIME YOU HAVE TAKEN TO IMPROVE MEASUREMENT OF WHEELCHAIR OUTCOMES FOR CHILDREN.

APPENDIX P

FUNCTIONAL MOBILITY ASSESSMENT - FAMILY CENTERED (FMA-FC)

Beta-Version 4

Functional Mobility Assessment – Family Centered version (FMA-FC)

DIRECTIONS:

STEP 1: Please answer the following 10 questions by **circling the words** (completely agree, mostly agree, etc.) or circling the percent of agreement (100%, 80%, etc.) that best matches your child's ability to function in his/her wheelchair. All examples may not apply to your child, and there may be tasks you perform that are not listed. **Mark each question only one time.** If you answer, ***slightly, *mostly, or *completely disagree – or answer 40%, 20% or 0% for any question,** please **write and specify the reason for your disagreement in the *Comments* section.**

STEP 2: To determine your priorities, review the content each of the 10 questions then choose the 3 most important questions. Rate **the importance of the content in those the 3 questions for your child** in the shaded box to the right of each question. Using the numbers 1 through 3, rate your family's highest priority for your child as "1" and the lowest priority as "3."

What percent of time does your child use the following means of mobility each day: Walking____% Crawling_____% Cane_____% Walker_____%
Scooter______% Manual wheelchair_____% Power wheelchair_____% Stroller_____%

1. My child's current means of mobility allows our family to participate in our daily routines as independently, safely and as easily as possible: *(e.g., tasks we want to do, need to do, are required to do- when and where needed)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	Rating priority
Comments:								
2. My child's current means of mobility meets his/her comfort needs: *(e.g., heat/moisture, ability to sit for a long time, pain free)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	
Comments:								
3. My child's current means of mobility meets his/her postural support needs: *(e.g., no redness or sores on skin, good support for breathing, decreased or no swelling, maintain sitting balance while completing activities)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	
Comments:								
4. My child's current means of mobility allows for managing daily supplies: *(e.g., Medical – ventilator, oxygen, suction, catheter tubing)* *Personal – computer, braces, phone, lunch etc.)*	Completely Agree 100%	Mostly Agree 80%	Slightly Agree 60%	*Slightly Disagree 40%	*Mostly Disagree 20%	*Completely Disagree 0%	Does not apply	
Comments:								

	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	Rating priority
5. My child's current means of mobility allows for access and completion of tasks at different surface heights as independently, safely and easily as possible: *(e.g., get under desks, tables, counters, floors, shelves)*	100%	80%	60%	40%	20%	0%		
Comments:								

	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
6. My child's current means of mobility allows for ease of transfers with or without help from one surface to another: *(e.g., bed, toilet, chair)*	100%	80%	60%	40%	20%	0%		
Comments:								

	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
7. My child's current means of mobility allows for completion of personal care tasks easily: *(e.g., dressing, toileting care, eating, washing, brushing teeth)*	100%	80%	60%	40%	20%	0%		
Comments:								

	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
8. My child's current means of mobility allows for movement freely and easily around our environment indoors AND outdoors: *(e.g., indoors = home, school, mall, restaurants – outdoors = playgrounds, uneven surfaces, grass, gravel, ramps, obstacles)*	100%	80%	60%	40%	20%	0%		
Comments:								

	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
9. My child's current means of mobility allows for independence from family/caregiver for desired activities: *(e.g., socialize, provide Bluetooth accessibility, accessible to peers)*	100%	80%	60%	40%	20%	0%		
Comments:								

	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply	
10. My child's current means of mobility allows for use of school, personal or public transportation as safely and easily as possible: *(e.g., secure, fold and store, ride)*	100%	80%	60%	40%	20%	0%		
Comments:								

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